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Stress in Mothers of Newly Diagnosed Children with Autism Spectrum Disorders: Barriers to Care, Use of Support Services, and Child Behavior

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STRESS IN MOTHERS OF NEWLY DIAGNOSED CHILDREN WITH AUTISM SPECTRUM DISORDERS: BARRIERS TO CARE, USE OF SUPPORT SERVICES, AND CHILD BEHAVIOR

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Dissertation Approval

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Abstract

A reasonable amount of parenting stress is not only expected, but often adaptive (Deater-Deckard, & Scarr, 1996); however, in the presence of chronically high levels of stress, negative outcomes are common. Parents of children with special needs, particularly autism spectrum disorder (ASD), are especially vulnerable to the presence of clinically significant levels of stress, making this group an important focus in the prevention of negative outcomes. The purpose of the present study was to determine the contribution of barriers to care, social support, and child behavioral problems to stress levels of parents with a child newly diagnosed with ASD. It was hypothesized that more support services and fewer barriers to care 6 months post diagnosis would moderate the association between parental stress at baseline and at 6 months. Findings provided preliminary evidence to support portions of the proposed model. Mothers who reported low stress at baseline demonstrated increased stress over time when exposed to even a moderate number of barriers to care. In contrast, mothers with high levels of stress did not demonstrate changes in stress levels as a result of reported barriers to care. Child behavioral problems and social support were not associated with parental stress over time. The application of findings to stress management programs, public policy, and future research are discussed.

TABLE OF CONTENTS

List of Tables

List of Figures

Chapter One: Introduction

Statement of the Problem

Parenting presents a universal challenge; however, providing care to a child with disabilities comes with unique demands (Baker-Ericzen, Brookman-Frazee, & Stahmer, 2005). Unlike typically developing children, children with special needs, particularly autism spectrum disorders (ASD), require additional attention and supervision from caregivers, specialized medical care, and therapeutic interventions. With the prevalence of ASD estimated at one in 88 children, the number of families caring for a child with ASD has increased rapidly, while the availability of effective supports has grown slowly (CDC, 2014). Most concerning in the domain of family support is that parents of children with ASD experience notably higher rates of parental stress compared to parents of typically developing children and children with other disabilities or health concerns (Blacher & McIntyre, 2006; Olsson & Hwang, 2001; Pisula, 2003). Preliminary evidence exists to support posttraumatic stress symptoms in parents after receiving an initial diagnosis of ASD for their child (Casey et al., 2012). Given this information, it is not surprising that some researchers have found stress to be a barrier for parents as they develop an appreciation for the positive aspects of their child (Kayfitz, Gragg, & Orr, 2010).

In the first year following a diagnosis, parents may struggle with the loss of dreams associated with their expected typically developing child. The implications of deficits in the areas of communication, social interaction, play, and behaviors that are specific to children with ASD may have a unique impact on parenting. Specifically, difficulties with social reciprocity, engagement in idiosyncratic behavior (e.g.,

unpredictable and inappropriate actions), and co-occurring externalizing behavior (i.e., temper tantrums, aggression) have been shown to exacerbate stress in parents of children with ASD (Lecavalier, Leone, & Wiltz, 2006; Tehee, Honan, & Hevey, 2009).

Parents are called upon to coordinate and advocate for access to intensive treatment services (i.e., up to 40 hours per week) for their children, including special-education services and specialized educational placements, as well as respite care. These intensive services may come with additional financial burdens that contribute to stress; however, research supports the critical importance of starting therapeutic interventions as early as possible to ensure the most optimal outcome for the child. If parents encounter multiple barriers in obtaining care and consequently utilize a limited number of support services, they are generally more likely to experience high levels of ongoing stress (Bishop, Richler, Cain, & Lord, 2007; Huws, Jones, & Ingeldew, 2001; Sivberg, 2002; Weiss, 2002). While some parents of children with disabilities cope well with their new roles and become strong advocates for their children, this result appears to be more the exception than the norm (Cassidy, McConkey, Truesdale-Kennedy, & Slevin, 2008). Many other families experience a chronic level of stress that impacts their overall quality of life, level of functioning as a family unit, and ability to parent effectively (Donenberg & Baker, 1993; Hastings & Brown, 2002; Lovell, Moss, & Wetherell, 2012; Rodrigue, Morgan, & Geffken, 1990).

Child rearing and accessing support can be stressful for all families, but these challenges are exacerbated in families raising a child with autism. A number of variables are suspected to contribute to the paradigm of parenting and seeking support. Although child characteristics, use of available support services, and barriers to care have been

suggested as possible explanations for elevated stress in parents of children with ASD, the literature remains inconclusive regarding specific contributions of these variables to overall parental stress in this population. Nevertheless, the existence of high levels of stress in parents of children with ASD is well documented. Thus, understanding the mechanisms that influence parental stress over time becomes pivotal to ensuring positive outcomes for children with autism and for their families' quality of life.

Purpose of the Study

This study evaluates if use of support services and if barriers to care moderate parental stress in mothers of children with ASD over the initial 6 months post diagnosis. This study aims to add to the literature by evaluating a parsimonious model of parental stress specific to the critical months after receiving an initial diagnosis through the evaluation of use of support services and the evaluation of barriers to care. Furthermore, the relationship among child behaviors, support services, and barriers to care is also evaluated. Ultimately, the identification of parents who are at risk for experiencing chronic levels of stress over time will be invaluable in developing targeted prevention and intervention programs to promote optimal functioning and a higher quality of life.

Chapter Two: Review of Relevant Literature

The Universal Existence of Parental Stress

A reasonable amount of parenting stress is not only expected, but also often adaptive (Deater-Deckard, & Scarr, 1996); however, in the presence of chronically high levels of stress, negative outcomes are common. For instance, the Yerkes-Dodson theory of arousal posits that a moderate level of anxiety is warranted to reach an optimal level of performance; however, high or low levels of anxiety can have negative implications on performance (Yerkes & Dodson, 1908). A parallel can be drawn with parenting, as a reasonable amount of stress can be adaptive, but further elevations at a chronic rate may hinder the most effective application of parenting skills.

The birth of a baby requires a great deal of adaptation on the part of a pre-existing family unit. Child rearing is a challenging and stressful process, even for the parents of typically developing children. New challenges surface throughout the child's development as parents are faced with naturally occurring developmental phases, such as the "terrible two's" and adolescent rebellion (Crnic & Greenberg, 1990; D'Angelo & Omar, 2003; Kwon, Han, Jeon, & Bingham, 2013). Therefore, parental stress, defined to include specific elements of parenting as perceived by the caregiver to cause distress (Abidin, 1990) is clearly present in the general population (Crnic & Greenberg, 1990; D'Angelo & Omar, 2003; Kwon et al., 2013). Ostberg and Hagekull (2000) proposed a model in which parental stress is associated with child temperament, caretaking hassles, and low social support. Research suggested that self-reported elevations in parental stress led to symptoms of fatigue and subsequent decreases in parental self-efficacy and parenting satisfaction in a sample of typically developing young children (aged 0-6 years;

Dunninga & Giallo, 2012). Parenting children with special needs, however, brings additional obstacles to an already challenging process and warrants specific consideration.

Stress in parents of children with special needs. The challenges of parenting a child with special needs are vast and vary greatly, depending on the specific type of disability. Children with developmental disabilities, physical limitations, vision and hearing impairments, chronic medical conditions, and behavioral challenges demand a level of expert skill that goes above and beyond that expected when parenting a typical child. Having children with special needs, such as behavioral disorders (e.g., impulsivity, hyperactivity, oppositionality) and medical issues (e.g., hearing impairment and diabetes), has been linked to increased parental stress levels (Hilliard, Monaghan, Cogen, & Streisand, 2011; Quittner et al., 2010). In addition to higher parental stress levels, parents of children with developmental delays also experience poorer health and a lower sense of coherence when compared to parents of typically developing children (Oelofsen & Richardson, 2006). Sense of coherence, a construct used to describe a common set of attributes among resources (e.g., social support), contributes to resilience and the promotion of health (Antonovosky, 1979).

Children with developmental disabilities and behavioral challenges have received much attention from the research community in regard to elevations in parental stress levels. ASD, a specific classification of a developmental disability, has surfaced in the literature as the population exemplifying the highest levels of parental stress as compared to both typically developing children and children with other disabilities and behavioral challenges.

What is an Autism Spectrum Disorder (ASD)?

Leo Kanner, a physician, was the first person to clearly describe autism through clinical experience and observation. In 1943, Kanner defined autism as immersion within oneself. He viewed social withdrawal as the primary feature of this new disorder and noted that children with autism did not show a preparatory response to being picked up, such as making eye contact or reaching out for their parents. In addition, he characterized children with autism as being content to play alone, treating people as objects, having an insistence on sameness, and having a significant language impairment, which he deduced to be a result of the social isolation (Kanner, 1943). This characterization of autism broke from tradition, with not merely a modification of adult criteria, but rather a distinct disorder with onset specific to the developmental stages of infancy or early childhood. The modern understanding of ASD as described in the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5) consists of: (a) impaired social communication and social interaction as well as (b) restricted, repetitive patterns of behavior, interests, or activities (American Psychiatric Association, 2013).

Approximately half of children with autism receive a concurrent diagnosis of an intellectual disability; however, researchers have indicated a wide range of findings (i.e., 25 - 75 %), making the true incidence of comorbidity unclear (Bölte & Poustka, 2002; Chakrabarti & Fombonne, 2001; Fombonne, 1999). The variability in these percentages may be due in part to the nature of the disorder, as results from IQ tests may not accurately reflect the true abilities of children with autism. For instance, the impaired language characteristic of autism creates a significant barrier to optimal performance on verbal tasks. In addition, difficulty with imitation skills, along with repetitive behaviors

and fascinations with objects, may impede the ability of a child with autism to successfully complete performance tasks. In many cases, children with autism also exhibit other problem behaviors, such as excessive food selectivity, anxiety, and sensory sensitivities (Levin & Carr, 2001). In considering the complicated phenotypic profile of a child with autism, high stress levels noted in parents of these children are a common occurrence (Pisula, 2003).

Diagnosing ASD

A select group of professionals is specialized in the diagnosis of an ASD. These individuals include clinical psychologists, developmental pediatricians, and neurologists, although this list varies slightly by state. Kanner's initial conceptualization included precursors of ASD to be present at birth; however, recent research illustrates significant trends of ASD markers not observed until 6-12 months of age (Bolton, Golding, Emond, & Steer, 2012; Ozonoff, 2010). Even so, the typical age at which an ASD diagnosis is offered varies greatly, depending on a variety of factors. Specifically, research supports variations in age of diagnosis as a result of difference in ethnicity, health care coverage, behavioral symptoms, and overall level of severity (Maenner et al., 2013; Mandell et al., 2010; Valicenti-McDermott, Hottinger, Seijo, & Shulman, 2012). The age of the child is important to consider, particularly in regards to the understanding of parental stress, for a variety of reasons: (a) the stages of childhood development come with unique challenges, even in the case of typical growth, that is the demands of parenting are different with a child in the preschool years, school-aged years, or adolescence; (b) specific transitions in childhood present a significant challenge, specifically for children with an ASD diagnosis (i.e., cooperative play, group play, friendship demands); and (c) age of the child has

demonstrated differences in service utilization. Therefore, examining cohorts of children of similar age appears to be most appropriate.

The widespread effects of ASD: A public health epidemic. The Centers for Disease Control (CDC) reports one in 88 children meet the criteria for an ASD, which is more than for cerebral palsy, hearing loss, vision impairment, and childhood cancer (CDC, 2014). The unique cluster of symptoms related to an ASD diagnosis impacts multiple domains of life for the affected child, as well as for the family unit. As previously stated, parents of children with ASD exhibit high levels of stress, more than that exhibited by parents of children with other neurodevelopmental delays (Dabrowska & Pisula, 2010). This chronic stress can lead to negative outcomes for parents, including, but not limited to, physical symptoms (e.g., exhaustion, muscle tension, headaches, and decreased immune system functioning) and mental-health concerns (e.g., depression and anxiety). These negative parental outcomes have been linked to decreased treatment gains for children with ASD (Lessenberry & Rehfeldt, 2004; Osborne, McHugh, Saunders, & Reed, 2008; Singer, 2006).

Stress in parents of children with ASD. Parental stress in families of children with ASD has remained a clinical area of concern, despite increased knowledge and public awareness of the disorder (Cassidy et al., 2008; Pottie & Ingram, 2008). The association between parenting a child with ASD and increased stress relative to parenting typically developing children or children with other disabilities has been demonstrated through decades of research with various stress measures (Baker-Ericzen et al., 2005; Crnic & Greenberg, 1990; Fisman, Wolf, Ellison, & Freeman, 2000; Hastings, Daley, Burns, & Beck, 2006; Hoffman, Sweeny, Hodge, Lopez-Wagner, & Looney, 2009;

Sanders & Morgan, 1997; Zeanah Berlin, & Boris, 2011). Furthermore, evidence exists to support that not only do a greater number of parents of children with ASD reach the threshold for clinically significant stress but the level of stress they experience is also greater in comparison to that experienced by parents of other groups of children (Hastings, 2008; Hastings et al., 2006).

One study examined predictors of maternal stress in a sample of 75 mothers of children with autism and other intellectual disabilities aged 3-19 years (Hastings et al., 2006). Although 56% of the mothers of children with other intellectual disabilities reported clinically elevated stress levels, 75% of the mothers of children with ASD were above the clinical cut-off (Hastings, 2008). Even more striking is that a greater number of the mothers of children with ASD reported a greater level of stress as well, as evidenced by higher mean scores on the Parenting Stress Index-Short Form (PSI-SF). This stress profile indicates that mothers of children with ASD experience clinical levels of stress more often and of a higher intensity than those experienced by mothers of children with other disorders. Furthermore, this stress remained stable over a 2-year time period, and findings have since been replicated, highlighting the importance of understanding the maintaining variables of stress in families of children with ASD (Dabrowska & Pisula, 2010; Hastings et al., 2006; Hastings, 2008; Wang, Michaels, & Day, 2011).

Although caregivers of children with ASD clearly experience high levels of stress, the findings are mixed regarding the amount and correlates of stress between mothers and fathers. Some studies report similar levels of stress in both mothers and fathers (Hastings, 2003; Rimmerman, Turkel, & Crossman, 2003), while more recent studies indicate significantly higher levels of stress in mothers (Dabrowska & Pisula, 2010;

Herring et al., 2006; Tehee et al, 2009). The cause of stress may differ for mothers and fathers as well. For instance, fathers' stress is associated, at least in part, to the stress experienced by their spouses; however, the converse is not true, in that mothers' stress is not associated with fathers' stress (Trute, Worthington, & Hiebert-Murphy, 2008).

Maternal stress may stem from children's regulatory problems, such as eating, sleeping, or emotional regulation, whereas fathers' reported stress is more often from children's externalizing behaviors (Davis & Carter, 2008). These different associations may relate to the fact that mothers are most often identified as the primary caregivers and therefore experience a higher level of involvement in the daily demands associated with caregiving for a child with ASD, including behavior management, accessing intervention, experiencing more frequent social stigma in the community, and role restriction (Davis & Carter, 2008; Tehee et al., 2009). In this regard, it is not surprising that some studies indicate fathers report indirect effects of stress through their partner's experience with their child with ASD (Gray, 2003). Although varying levels and correlates of stress have been noted in mothers and fathers, negative consequences of stress are universal and may include decreased relationship satisfaction with their child with ASD, as well as more direct effects on parental well-being (e.g., mental health) and quality of life. Exploring the stress profile of mothers and fathers of children with ASD separately may offer a more comprehensive understanding of the maintaining variables at play. Furthermore, isolating maternal stress may provide evidence to guide a more efficient method of exploring the presentation of stress in fathers (Trute et al., 2008).

Effects of Stress in Families of Children with an ASD

The negative effects of stress in rearing children with ASD can include influences on maternal mental health, interpersonal relationships, and social adjustment. The impact of stress associated with parenting children with developmental conditions can also vary, depending on the child's symptoms, the occurrence of challenging behaviors, and the child's developmental progression over time. Additionally, the chronic nature of this stress, as is the case in lifelong developmental disabilities, is also worthy of mention.

Negative effects of parental stress on parental well-being.

Mental health. Daily stress has been associated with negative mood states (e.g., anxiety and depression) in parents of children with ASD (Hamlyn-Wright, Draghi-Lorenz, & Ellis, 2007; Pottie, Cohen, & Ingram, 2009; Pottie & Ingram, 2008). A meta-analysis of 18 studies illustrated consistent findings of increased depressive symptoms in parents of children with developmental disabilities, with more pronounced symptoms in parents of children with ASD (Singer, 2006). As mentioned previously, differences between mothers and fathers have been illustrated in self-reported parental stress levels. The same has been demonstrated in regards to psychosocial adjustment. Specifically, higher levels of depression and anxiety have been found in mothers when compared to fathers of high-functioning children with autism, further supporting separate evaluation of these roles (Lee, 2009). Negative outcomes extend beyond mental-health concerns (e.g., anxiety and depression) to more general quality-of-life issues, such as parenting competence and limiting the enjoyment that comes from the positive aspects of parenting

(Hastings & Johnson, 2001; Kayfitz et al., 2010; Rodrigue et al., 1990; Tomanik, Harris, & Hawkins, 2004).

Social and relationship adjustment. The negative impact of stress can have far reaching effects on areas outside of the caregiving role for parents of children with ASD, including marital satisfaction, family adaptability, functioning of siblings, and social isolation (Fisman et al., 2000; Kogan et al., 2008; Sanders & Morgan, 1997). Parents of children with ASD have been found to exhibit more negative adjustment (e.g., pessimism, distant relationships with the affected son or daughter, lack of family opportunity) compared with parents of individuals with Down syndrome, fragile X syndrome, and other disabilities (Abbeduto et al., 2004; Estes et al., 2009; Sanders & Morgan, 1997), some conflicting evidence shows that some parents of children with ASD report close attachments (Hoffman et al., 2009).

Parents reporting negative family functioning may also encounter fewer positive interactions with their child. An important study by Kayfitz et al., (2010) assessing caregiver perspectives on parenting a child with autism revealed fewer reported positive experiences and greater reported parental stress. Positive experiences were defined to include direct contributions from the child (e.g., source of happiness, improving family closeness), as well as indirect contributions of the child with special needs to the parent (e.g., personal growth, understanding life's purpose) as measured by the Positive Contributions Survey, a subscale on the Kansas Inventory of Parental Perception (KIPP; Behr, Murphy, & Summers, 1992). Taken together, an overwhelming amount of evidence supports the idea that the majority of families with a child with ASD experience personal and relationship strains including marital satisfaction, parenting competence, and family

adaptability more so than parents of children with Down's Syndrome and typically developing children (Rodrigue, Morgan, & Geffken, 1990).

Negative effects of parental stress on child outcomes.

Parental stress has direct negative effects on parental well-being; the effects of such strain extend to their children. High parental stress levels have been associated with increased child behavioral problems and less-than-optimal outcomes from treatment interventions, which can hinder the developmental progression of a child with ASD (Daley, Sonuga-Barke, & Thompson, 2003; Osborne et al., 2008). The negative influence on child outcome further highlights the importance of understanding the most salient contributing variables to the unique stress profile in parents of children with ASD.

Children of parents who experience a high degree of stress have been associated with a variety of negative behaviors, such as conduct problems, attention deficit hyperactivity disorder (ADHD), and obsessive-compulsive disorders (Daley et al., 2003; Steketee, Van Noppen, Lam, & Shapiro, 1998; Vostanis, Nicholls & Harrington, 1994). Some suggest a bidirectional association between child behavioral problems and parental stress such that child behavioral problems have been described as both a negative outcome of parental stress and as a potential cause of such stress.

Parental stress can negatively impede a child's progress and response to effective treatment/interventions. High parental stress has been correlated with limited progress on treatment goals and educational objectives for children with ASD. Osborne et al. (2008) found that increased parental stress at the onset of professionally implemented teaching intervention programs for preschoolers with ASD was associated with fewer

developmental gains in areas of educational and adaptive functioning for children receiving more than 15.6 weekly hours of service (Osborne et al., 2008). A similar association has been identified between parental stress and child outcome variables in parent implemented intervention (Carlson-Green, Morris, & Krawiecki, 1995; Plienis, Robbins, & Dunlap, 1988). Specifically, increased stress experienced by parents is associated with significantly lower rates of developmental gains in their respective children (e.g., 3 month's vs. 15 months' improvement over a 1 year period; Robbins, Dunlap, & Plienis, 1991). One reason for these less promising outcomes is likely lower treatment adherence. When parents experience high levels of stress, their cognitive and emotional resources are compromised, negatively affecting their ability to carry out important generalization components of treatment regimens (Rao & Beidel, 2009). Taken together, the negative effects of stress on parental mental health, social and relationship adjustment, and characteristics of the child (i.e., problem behaviors, developmental functioning) provide a solid argument for the importance of determining the causes and correlates of such stress in parents of children with ASD.

Chronicity of stress in parents of children with ASD

Stress in caregivers of children with ASD produces negative outcomes on both maternal well-being and child outcome as previously outlined, suggesting a multivariate integrated approach to the understanding of stress in this population. By definition, autism is a "spectrum" of disorders, and the cause of varying presentations is unclear. What is known is that each child with ASD presents with a unique combination of deficits and strengths. Furthermore, these unique symptom presentations change with the passage of time, such as the growing academic and social demands of childhood. As

children progress through different stages in development, new symptom foci may naturally occur. Thus, understanding the trajectory of stress over time for families of children with ASD may require a longitudinal approach including frequent check points over time so that smaller time segments can be examined.

Life Stages and Transitions

One of the few longitudinal studies to date exploring parental stress in a sample of individuals with intellectual disabilities found that parents maintained a high level of stress from initial diagnosis to discharge from school over a 7-year period (Baxter, Cummins, & Polak, 1995). Initial diagnosis was indicated as the most stressful life event; however, other transition experiences (e.g., child entering school, moving into the work force) also correlated with higher levels of parental stress. Notably, data at the time of initial diagnosis were recorded retrospectively and thus suspect to retroactive interpretation. In addition, the measure of stress was non-specific and may not have captured the complexities of strain on parents of individuals with disabilities. Nevertheless, the findings of Baxter et al., (1995) represent an important foundation for the longitudinal investigation of stress in parents of children with special needs.

One 10-year longitudinal study exploring the qualitative psychosocial adaptation of parenting an individual with autism found that approximately two thirds of parents reported a better state of psychological well-being at the end of the 10 years as compared to earlier in their lives (Gray, 2002). Although this study included parents of children between the ages of 4-19 years the study did not differentiate time since initial diagnosis, and thus each participant may have been in a different stage of treatment and/or services. Furthermore, many pendulum changes take place throughout the course of a decade, and

although examining this trajectory is helpful, it may be more fruitful for the purposes of intervention examining smaller time segments in more detail. Ideally, professionals can identify the factors differentiating resilient parents and those at risk for developing high parental stress to lead to more efficient and effective interventions. In particular, half of those involved in the 10-year longitudinal study by Gray (2002) reported continued anxiety and depression and only one third of parents reported receiving professional help in coping (e.g., psychotherapy, medication). As reported by these parents, characteristics of the child with ASD, including aggressive behaviors and severe obsessions, were indicated as differentiating the sample in regards to reported stress levels. Furthermore, anxiety about the child's future and difficulty managing aggressive behavior tend to increase over time (Gray, 2002). Therefore, focusing on support services as an essential treatment component during the first year after diagnosis, regardless of child's age, might offset the potential trajectory of stress over time.

Subset of resilient parents

One must also consider that although the population of caregivers for children with ASD experience significantly high levels of stress as a group, caregiving and stress is not a simple cause-and-effect relationship. In other words, having a child with ASD does not automatically determine a clinical level of parental stress. Positive adjustment to the parenting role of a special-needs child and effective coping strategies have been noted in a select number of parents (Carr, 2005; Flaherty & Masters Glidden, 2000; Glidden & Johnson, 1999; Hastings, Kovshoff, Brown, Ward, Espinosa, & Remington, 2005). Furthermore, highlighting the contribution of recent research on the positive effects of parenting a child with autism is certainly important, given evidence that supports these

positive experiences may serve as protective factors against the negative outcomes of parental stress, thereby leading to both physiological and psychological benefits to the family unit (Kayfitz et al., 2010; Salovey, Rothman, Detweiler, & Steward, 2000; Tugade & Fredrickson, 2004).

Several studies have examined factors related to resilience and well-being among parents of children with ASD (Greeff & van der Walt, 2010). Parents noted that breaks from round-the-clock care and increased feelings of control were helpful in coping with their caregiving role (Freedman, Griffiths, Krauss, & Seltzer, 1999). In a mixed-sample study of children with special needs performed by Snell and Rosen (1997), several parents saw themselves as having an increased purpose in doing what every parent would see as the "normal stuff." The parents attributed problems to the disorder instead of to themselves, viewed the child as having a special purpose, and themselves as being in control.

The presence and use of social support has also been cited as a beneficial factor in successful coping in parents of children with special needs (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). Specifically, aspects of social support and coping styles moderated the relation between stressors and negative outcomes, such as depression, social isolation, and spousal relation problems (Dunn et al., 2001). Variability in stress profiles presents a challenge in delineating the specific sources and reactions to stress. Thus, child (e.g., behavioral problems), parent (e.g., mental health), and environmental (e.g., social support, access to care) variables clearly should be considered when determining the trajectory of stress over time (Lecavalier et al., 2006; Singer, 2006).

Correlates of stress in parents of children with ASD

A number of variables have been associated with the stress experienced by parenting a child with ASD. First, the unique impact of the symptomatology of ASD has received a substantial amount of attention in the literature in regards to the impact on parental stress levels. Specifically, child behavioral problems have been cited to have a bidirectional relationship in the parental stress literature, in which high rates of one are associated with increased rates of the other and visa versa. Second, is the use of social supports that parents choose to seek or not pursue in the care of their child with ASD (e.g., obtaining knowledge about the disorder, specific advice on the management of behavioral problems). Last, many parents report significant barriers to obtaining care and support as they navigate a complicated process of diagnosis, treatment, and management of a lifelong developmental disability in their child. These three variables, child characteristics, social support, and recourses, have been conceptualized in a comprehensive model of stress in families of children with developmental disabilities (Perry, 1989, 2004). Earlier studies looking at these variables found the largest proportion of variance (27-34%) in stress resulted from parental perception of child behaviors (e.g., how bothersome is this particular symptom) in a sample of 61 parents of children with ASD (Perry, 1990); however, more than half of the variance remains to be explained by factors outside of the subjective perspective of child behavioral symptomatology. More recent studies indicate parental stress levels were associated with objective characteristics of the child, such as a discrete level of skill, rather than a subjective interpretation (Baker-Ericzen et al., 2005, Tehee et al., 2009).

Child characteristics. Although children with ASD, by definition, exhibit impaired social functioning, communication deficits, and repetitive/restricted interests, comorbid diagnoses and associated features (e.g., problem behaviors, adaptive delays, impulsivity, intellectual disabilities, sleep difficulties, and sensory sensitivities) often complicate the development of a conclusive body of literature on the diagnostic impact of ASD on parental stress. For instance, some researchers have found that language, social skills, sensory interests, and self-help skills are associated with increased parental stress (Hastings & Johnson, 2001) whereas others highlight behavioral problems to be a principal contributor. Thus, the process of separating the impact of these specific variables (e.g., behavioral and developmental deficits) on parental stress levels remains complex (Tehee et al, 2009). Evidence also supports a reciprocal relationship between parental stress and child behavioral problems in children with developmental disabilities (Hastings et al., 2006; Lecavalier et al., 2006). Problem behaviors are often a target of intervention programs for children with ASD, as they are commonly observed in this population; however, outcome studies have illustrated professionally guided intervention efforts (i.e., behavior parent training) to be less effective in improving child behavior when parental stress variables (e.g., depression, sense of competence) were more salient at pretreatment (Plienis, Robbins, & Dunlap, 1988). This finding remained significant even when both groups of children had behavioral problems rated in the 95th percentile at baseline, highlighting parental stress as a variable negatively impacting the effectiveness of intervention efforts aimed to manage child behavioral problems (Plienis, Robbins, & Dunlap, 1988). Therefore, the importance of evaluating child behavior problems in the understanding of parental stress appears clear.

Problem behaviors. A common approach to understanding problem behaviors is dividing the behaviors into two categories: internalizing and externalizing behaviors. Internalizing behaviors are actions directed inward and are sometimes more difficult to directly observe. Behaviors in this first category include concerns such as somatic symptoms, anxiety, and withdrawn or depressive traits. In contrast, externalizing behaviors include actions directed outward, such as aggression, destruction, and tantrums. Children with ASD across a broad age range have been identified to have higher rates of both externalizing and internalizing behaviors, and their parents have higher rates of parent stress in comparison to typically developing children (Freeman, Perry, & Factor, 1991; Hastings et al., 2006; Lecavalier et al., 2006; Rao & Beidel, 2009; Weiss & Lunsky, 2011); however, these problem behaviors are not a unique facet of ASD and are commonly observed in other disorders of childhood.

Research has indicated a differentiated behavioral profile between ASD and other common childhood behavioral disorders, such as attention deficit hyperactivity disorder (ADHD), conduct disorder (CD), and learning disorders; Donenberg & Baker, 1993; Dumas, Wolf, Fisman, & Culligan, 1991; Efstratopoulou, Janssen, & Simons, 2012). Specifically, internalizing behaviors were found to be uniquely higher in a sample of children with ASD whereas the samples of children with ADHD and CD showed higher externalizing behaviors when compared to children with ASD (Efstratopoulou et al., 2012). In addition, unpredictable and ritualistic behaviors have demonstrated the highest correlation in relation to parental stress in samples of children with ASD whereas other authors report no correlation (Davis & Carter, 2008; Lecavalier et al., 2006; Tehee et al., 2009). Of note is that problem behaviors specific to ASD (i.e., ritualistic and stereotyped

actions) are not uniformly classified as internalized or externalized behaviors, confounding a succinct understanding based on broad behavioral categories rather than more isolated behaviors. Even so, although behavioral problems appear to be associated with increased parental stress in a variety of childhood disorders, markedly higher levels of stress continue to be paramount in families of children with ASD.

The previous evidence suggests that parents of children with ASD have levels of stress higher than those of parents of children with other disorders, even when the impact of child behavioral problems is controlled. Some of the observed variability in these findings can be attributed to inconsistent operational definitions, making the delineation of contributing variables for empirical study a challenging task. Improving the consistency with which researchers investigate problem behaviors with similar operational definitions will likely serve to clarify the influence of each of these presenting symptoms on parental stress. Child behavioral problems are also associated with impaired social interactions, as peers may shy away from overtly disruptive actions and/or those sitting quietly withdrawn in a corner alone.

Research has also provided some evidence for the contribution of other key characteristics in the clinical presentation of ASD, such as deficits in social skills, communication challenges, delays in adaptive functioning, and cognitive impairments on parental stress levels; however, the impact of these variables is unclear as compared to the salient nature of child behavioral problems. Evidence exists to support delays in social development as correlates to increased parental stress in newly diagnosed toddlers with ASD, as well as in those completing intervention programs (Baker-Ericzen et al., 2005; Davis & Carter, 2008). These findings do not go unchallenged, however, as other

researchers have noted that delays in communication and daily living skills were more salient contributors to parental stress levels than social-skills deficits (Hall & Graff, 2011). Furthermore, some studies have reported social skills deficits to be responsible for less than 5% of the variance in parental stress levels, thus supporting the evaluation of other factors (Lecavalier et al., 2006). In regards to cognitive functioning, consistent stress levels were found between parents of children with autism exhibiting IQ < 50 and parents of children with autism exhibiting IQ > 50 (Koegel, Schreibman, Loos, & Dirlich-Wilhelm, 1992). Stress levels of parents in a sample of children with ASD with at least average intelligence on standardized measures of IQ remained significantly higher than those parents in a control group (Rao & Beidel, 2009). This finding provides some evidence that the classic stress profile in the parents of children with ASD is the result not solely due of cognitive deficits; however, other characteristics of the child, such as behavioral problems, seem to play significant roles in stress levels and lead parents to seek various kinds of support (Boyd, 2002).

Understanding Parental Support

The use of support services, perceived helpfulness of support, and barriers to obtaining available supports are important areas to assess as parents of children with ASD manage a unique set of demands in the care of these special children. Support has been divided into different categories in an effort to better understand specific influences; however, varying perspectives on those divisions can cloud the underlying importance of the sources of that support. Some researchers offer two mutually exclusive categories of support: formal (advice or services provided through professional organizations or agencies) and informal (immediate and extended family, neighbors, friends, other

parents; Boyd, 2002) whereas others classify support based on “general” (emotional support and normalization of concerns) versus “specific” (parenting support, advice from professionals; Guralnick, Hammond, Neville, & Connor, 2008). Therefore, discussing the source of support (i.e., who) rather than a categorical classification may be more fruitful.

As might be expected, evidence exists substantiating the importance of social supports. Parents of newly diagnosed children showed greater reductions in self-reported stress levels when provided with professional support. Specifically, an intervention was designed and disseminated in two formats to provide education and strategies targeting areas commonly affected by ASD (e.g., social, communication, play). The first intervention, a professionally guided format, included a 2-day workshop followed by 10, 1-hour home consultation visits. The second intervention included the same information in a self-directed, video-based model with no in-person or hands-on professional guidance provided (Keen, Couzens, Muspratt, & Rodger, 2010). Parents who received the direct professional support showed greater reductions in self-reported stress levels than parents who did not. Informal supports have also shown promise regarding increased effectiveness in stress reduction in parents of children with ASD (Boyd, 2002; Bristol, 1984; Greeff & van der Walt, 2010; Hastings & Johnson, 2001). During a professionally guided intervention to reduce stress, parents reported their most positive experience as the informal support provided by other parents in the group (Krauss, Upshur, Shonkoff & Hauser-Cram, 1993). In addition, as evidence supports varying stress profiles in mothers and fathers of children with ASD, one study reported that the emotional support provided by both maternal and paternal grandmothers was associated with lower parental stress levels whereas fathers reported stress levels were correlated only with their partners’

experiences rather than directly with provided support from grandmothers (Trute et al., 2008). Taken together, these data suggest an important role for both formal and informal social supports in the reduction and management of stress levels in mothers of children with ASD.

Benefits of support services. Regardless of the nature of support, existing evidence suggests that social support consistently alleviates parental stress and results in reductions of anger, guilt, and anxiety in parents of children with ASD (Bishop, Richler, Cain, & Lord, 2007; Bristol, 1984; Cappe, Wolf, Bobet, & Adrien, 2011; Dyson, 1997; Gray & Holden, 1992; Pottie et al., 2009; Sharpley, Bitsika, & Efremidis, 1997; Tehee et al., 2009; Wolf, Noh, Fisman, & Speechley, 1989). In fact, Carter (2005) illustrated greater reductions in anxiety and depression related to stress when parents participated in a focused social support group compared to a stress inoculation training group. Furthermore, social support has been illustrated to result in positive coping benefits for parents of children with ASD in the areas of resilience and adaptation, psychological and physical health, family functioning, and overall impact (Siman-Tov & Kaniel, 2011). Given that the chronicity of ASD symptoms can lead to burnout in parents expected to manage the multiple service needs of their children (e.g., treatment planning, adaptation, financial considerations; Cassidy et al., 2008; Wagner, 2011), it should not be surprising that many researchers have linked support services with lower levels of stress, particularly in populations at increased risk for high levels of stress, such as is the case in ASD.

Research has suggested that social supports help families cope with the stress of raising a child with ASD by providing respite from the chronic nature of the disorder and

improving overall quality of life (Factor, Perry, & Freeman, 1990; Khanna et al., 2011; Marc & MacDonald, 1988). In fact, parents of children with ASD reported school and staff services, respite care, and family as the three top facilitators of stress relief (Tehee et al., 2009). Support from friends and relatives (i.e., understanding rather than instrumental support) and spiritual beliefs can be significant contributors to resilience and successful adaptation in parents of children with ASD, as well (Greef & van der Walt, 2010; Sharpley et al., 1997; Weiss, 2002). The opportunities to connect with others might also serve to bolster parents' belief in the efficacy of the recommended interventions for their child, which is also associated with lower parental stress levels, even when the child is displaying more severe impairments in functioning (Hastings & Johnson, 2001). One should note that a subset of studies has found an association between high levels of parent stress and participation in more therapeutic services, although still is unclear whether parents who have higher stress have children with greater need, thus requiring more services, or whether the number of services themselves is stress inducing (Cassidy et al., 2008; Deater-Deckard, 1998; Smith, Oliver, & Innocenti, 2001; Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007).

Support services and quality of life. Given the majority of evidence presented, the use of support services is highly likely to significantly improve the overall quality of life in families of children with ASD. Parents who exhibit fewer physical and mental-health symptoms and increased self-efficacy may improve their ability to parent effectively (Bishop et al., 2007; Lovell et al., 2012; Weiss, 2002). Social-support interventions may result in indirect improvements in the relationships among family members (i.e., happier marital and sibling interactions), including better emotional

connectedness and increased positivity in interactions between parents and the child with special needs (Bristol, 1984; Dunn et al., 2001; Dunst, Trivette, & Cross, 1986; Rivers & Stoneman, 2003). Additionally, increased social support has been shown to reduce the perceived negative impact of financial stressors and increased social connectedness for parents of children with an ASD (Bishop et al., 2007; Dunn et al., 2001). With this increased connectedness, contact with other parents and professionals may also provide information about access to services and guidelines for navigating the barriers common to securing appropriate interventions for a child with ASD (Tehee et al., 2009). The importance of support services is clear; however, obstacles to obtaining supports for parents and services for the affected child need to be addressed for a comprehensive understanding of the stress profile in this population.

Barriers to Care

Various kinds of supports assist in easing the daily struggles faced by the entire human race. However, some are faced with additional obstacles, such as physical or mental-health concerns, criminal or legal action, homelessness, or financial debt. Although the majority of society can be self-sufficient, other groups, including young children, the elderly, and those with various handicaps, rely on the support of others for their survival. Therefore, one may assume that those providing care for these vulnerable populations require more support to meet the demands of caregiving. Moreover, experiencing barriers while attempting to access these supports and services can be detrimental not only to those seeking services but also to those they serve. In the case of children newly diagnosed with an ASD, their caregivers are called to navigate a range of complicated forums including public policy, personal resources, insurance mandates,

special education law, medical specialists, and treatment interventions, to name a few. Potential barriers to accessing appropriate care, in whatever form necessary, can lead to harmful outcomes for the caregiver as well as for the child in need of appropriate and effective care.

The medical home model of care. The importance of comprehensive care has been nationally recognized through the development of the medical home model of care created and implemented by the Academy of Pediatrics (AAP; The Medical Home, 2002). This model iterates that the standard of quality care should include elements of accessibility, comprehensiveness, family centeredness, compassion, coordination, and affordability. Although some researchers report overall success for children with special health care needs, results are not as favorable for children with autism (Brachlow, Ness, McPeeters, & Gurney, 2007; Strickland et al., 2004). Mothers of children with ASD have significantly more difficulty obtaining services when compared to mothers of children with Down syndrome (Mackintosh, 2008). In addition, more common medical conditions often correlated with ASD (e.g., congenital conditions affecting eyes, ears, central nervous system, heart, or urinary system) highlight the need for general medical care (Lauritsen, Mors, Mortensen, & Ewald, 2002); nevertheless, rather low rates of primary health care use have been reported in the population with ASD (Hall, Wood, Hou, & Zhang, 2007).

Many parents of children with ASD encounter challenges in obtaining an initial diagnosis, but may have a misconception that diagnosis is the hardest part in the process of obtaining appropriate care for their child. “Attaining supports and services,” “education,” and “understanding their child’s needs” were among the top contributors to

stress reported by parents of children with ASD (Thomas et al., 2007, p. 1905). Parents report more difficulty finding respite care and babysitters for children with ASD who display high rates of behavioral problems, which can lead to increased isolation and subsequent elevations in stress of parents (Sanders & Morgan, 1997; Young, Ruble, McGrew, 2009). In an interview completed by Minnes and Steiner (2009), one parent reported, "I'm going to get the autism diagnosis and all these services are going to fall out of the sky, and we're going to be helped" (p. 253); however, the disconnect between "parent beliefs" and "system realities" provides a recipe for frustration in an already stressful situation. A range of obstacles, collectively referred to as barriers to care, have been discussed in the literature as impacting a family's utilization of services. These obstacles include lack of knowledge, wait lists, financial and time considerations, and negative perception of available assistance (Young, Ruble, McGrew, 2009).

A vast array of research supports the efficacy of evidence-based treatments; however, the dissemination and application of such information is poor (Wilczynski et al., 2011). In one sample of 383 families of children with ASD under 11 years of age, 25-33% of families reported no use of a "major treatment approach" (Thomas et al., 2007, p. 1905; Tehee et al., 2009). This lack of treatment utilization represents a crucial deficit in service allocation and a significant contributor to parental stress levels. Specifically, parents of children 15-18 years of age reported lower amounts of access to information/education when compared to access for 3-6 year and 11-14 year age groups (Tehee et al., 2009). Also, families of children between 5-8 years of age reported accessing a package of services different from that accessed by families of children in 3-5 year and 9-11year age groups (Thomas et al., 2007). Notably, this latter study did not

examine the time elapsed between initial diagnosis and time of data collection; therefore, service use may vary depending on time from initial diagnosis rather than on specific age of child. Although the medical home model appears to present a sound theoretical ideal regarding the distribution of appropriate care, one must understand the factors contributing to the failing implementation of this model in the case of children with ASD and their families. Since problems accessing services can lead to feelings of isolation in navigating the system, barriers to care might present as a unique contributor to parental stress levels resulting from the necessary advocacy role that parents must take on for their children within a system that works against their efforts to obtain appropriate care (Minnes & Steiner, 2009).

Structural and Pragmatic Barriers to Care

Comprehensive system of diagnosis and treatment. Parents of children with ASD report that a more comprehensive approach to diagnosis and treatment and additional advice by the same provider would help close the gap between diagnosis and access to services and support (Minnes & Steiner, 2009). After diagnosis, many parents report dissatisfaction with professional guidance, citing inadequate follow-up information for navigating the steps to service access (Gray, 1994; Huws et al., 2001). Interestingly, parents who were referred to a social-support group by their diagnosing clinician were more likely to join the group, indicating that parents value professional guidance for available supports (Mandell & Salzer, 2007); however, parents clearly do not always receive comprehensive information following their child's diagnosis. Limited referrals from professionals following a diagnosis of ASD has been found to contribute to parents' hesitance toward accessing the service system, with subsequent decreases in service use

compared to use by other psychologically disordered populations (Edwards, 2003; Lau, Garland, Yah, McCabe, Wood, & Hough, 2004). Additionally, parents face practical challenges to accessing services, including family schedule constraints, lack of childcare, and difficulties with travel (Bennett, Rowe, & DeLuca, 1996; Burke & Cigno, 1996; Huws et al., 2001; Smith, Gabard, Dale, & Drucker, 1994).

Relationship with professionals. Even when caregivers obtain the necessary information to access services, they often report a perceived lack of compassion by service providers as additional barriers to care (Martinez, 2010). Some parents report interactions with professionals to be authoritarian, lacking parental input, and lacking collaboration (Knox, Parmenter, Atkinson, & Yazbeck, 2000). Parents who perceived professionals as having an understanding of their child's difficulties and needs reported lower levels of stress, highlighting the importance of professional knowledge regarding ASD and access of services (Sharpley et al., 1997).

Parents' education level, cultural and ethnic views on treatment use, and area of residence (i.e., nonmetropolitan) relative to distance from necessary services also have been linked to difficulties accessing care for autism-related services (Thomas et al., 2007). Minority race and ethnicity also have been linked to a delay in service use and different treatment package profile when compared to Caucasian counterparts (Levy, Mandell, Merhar, Ittenbach, & Pinto-Martin, 2003; Mandell, Listerud, Levy & Pinto-Martin, 2002).

Socioeconomic status and financial burden relative to service access is an area of concern. Owing to the need for intensive services for children with ASD, service access can often involve significant financial investment on the part of affected families;

however, similar to other variables implicated in parental stress, results at present are mixed with regard to financial impact and parental stress. The unclear impact of financial responsibility may be the case considering the many types of health care plans or state-specific mandates leading to vast differences in the expected contribution of individual families. General income levels of families have been found to impact the range of service use (Thomas et al., 2007). One qualitative study exploring the experiences of mothers of children with ASD found perceived barriers to include limited financial means and restricted medical insurance access (Martinez, 2010). Further, research on type of insurance coverage and out-of-pocket expenses relative to access to care has been inconsistent (Young et al., 2009). Parents of children with ASD who reported coverage by Medicaid or other public insurance had fewer problems accessing services compared to those with private insurance (Thomas et al., 2007). Specifically, those families with public insurance were more likely to access services (e.g., medication, respite care, case manager, and speech therapy). Surprisingly, parents of children with no health insurance were actually more likely than parents with insurance to access developmental pediatricians and case managers (Thomas et al, 2007). Even so, other studies have found no differences in service utilization or access to care based on type of insurance coverage (Liptak, Stuart, & Auinger, 2006; Young et al., 2009). These differences may be explained by variable operational definitions of access to care and/or state-dependent insurance laws that would make comparison among studies irrelevant (Young et al., 2009).

A theoretical understanding: The possible relationship among child behavioral problems, use of support services, barriers to care, and parental stress in ASD.

Many would agree that parenting a child with ASD presents additional demands in an already challenging role. From a cognitive-behavioral therapy (CBT) perspective, parents experience a range of thoughts, feelings, and behaviors as they learn the expectations of caring for a child with autism. At the initial diagnosis, parents are required to process a large amount of information at one time. For instance, some parents are unsure of a diagnosis whereas others are appreciative to finally receive "validation" of their concerns. A vast range of emotions, including surprise, denial, relief, and typically some level of inquisition or fear about the "next steps" can be observed at the time of an initial diagnosis. Caregivers begin to have questions about the meaning of this news means for their child, family, and future: "What do I do now?," "How can I manage my child's behavior?," "Will he/she be able to have a 'normal life'?" Unfortunately, even with increased awareness of ASD, some parents continue to ask if they did something to cause autism in their child. Taken together, receiving an initial diagnosis of ASD comes with a range of thoughts and feelings leading many parents to seek support.

One of the well-supported contributors to parental stress has been the presence of child problem behaviors (Baker et al., 2003; Herring &Wahler, 2003; Solem, Christophersen, & Martinussen, 2011). Children with ASD generally illustrate problem behaviors, including difficulties with transitions or changes in schedule, reliance on routines, noncompliance, aggression, hyperactivity, inattention, impulsivity, and/or anxiety. These challenging behaviors are difficult for parents to manage, contribute to

social withdrawal and isolation (i.e., limit community outings), and impact parental stress levels at the time of diagnosis. Often, these challenging behaviors lead parents to seek support services in an effort to obtain assistance in the management of their child's autistic symptomatology. Unfortunately, parents report many obstacles in their efforts to obtain services. For instance, some parents indicate a lack of guidance from professionals regarding the next steps after initial diagnosis, long waiting lists to obtain services, and underqualified or uncompassionate professionals. In addition, some families experience a lack of understanding from close family members, neighbors, and society at large whereas others report a significant amount of support from professionals and lay people in their social network. Parents receiving support services and encountering few barriers to care may be better able to cope with the initial transition to a diagnosis of ASD for their child than those parents who have limited access to support services. Parents who have support and few barriers to obtaining that support may then be better equipped to care for themselves, their affected child, and family. Taken together, one may hypothesize that an increased use of support services and simultaneous minimization of barriers to care during the initial 6 months following a diagnosis lessen the level of reported parental stress over this discrete period of time (Figure 1).

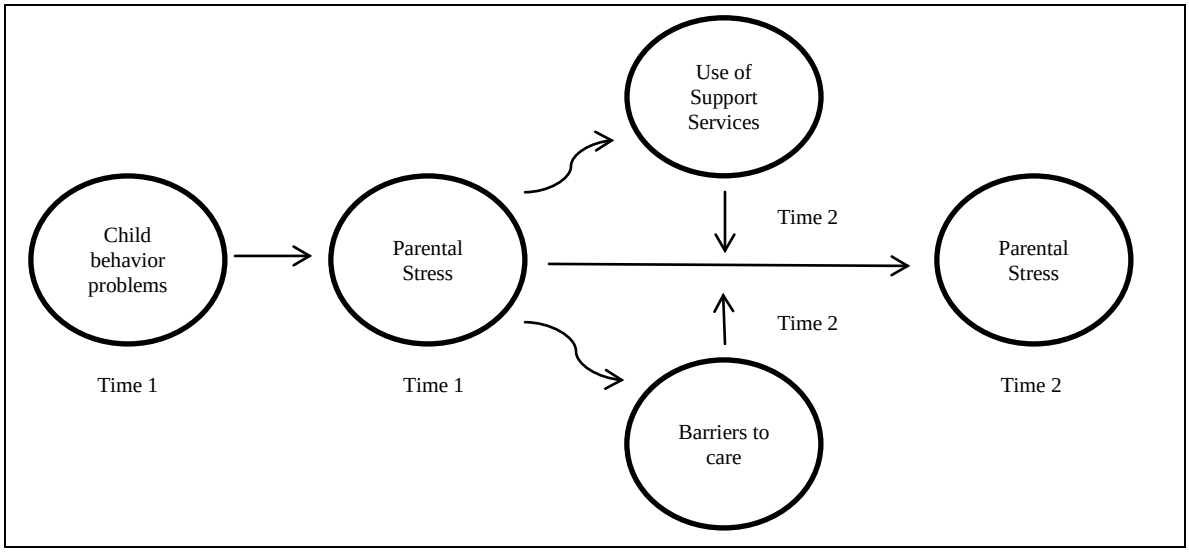

Figure 1. Model of stress in parents of children newly diagnosed with ASD.
Note. Time 1= Baseline; Time 2= 6 months post diagnosis.

The Current Study

Some of the variance in stress among parents of children with an ASD may result from barriers to care and social and service delivery. After obtaining an initial diagnosis, parents then have to navigate potential barriers to obtaining the most appropriate services for their child and may or may not have the knowledge of support services to aid in this venture. Moreover, each child on the spectrum presents with a unique combination of symptoms in regards to frequency, intensity, and impact on overall functioning. Although previous research has examined combinations of these variables, no studies to date have explored all three in the understanding of parental stress specifically during the first 6 months after an initial ASD diagnosis. This study examines the respective and

collective contributions of barriers to care, use of support services, and child symptom severity levels on parenting stress, with a specific focus on the first 6 months post diagnosis. By identifying critical variables implicated in the maintenance of chronic stress at the onset of diagnosis, preventive methods can be more easily applied to improve family functioning early on.

Chapter Three: Hypothesis

Research question: Are social support and barriers to care moderators of parental stress of mothers with a child newly diagnosed with ASD?

Hypothesis: Increased use of support services and decreased barriers to care at Time 2 (6 months post diagnosis) will moderate the association between parental stress at Time 1 and parental stress at Time 2. It is expected that lower levels of parental stress will be observed at Time 2 for those parents utilizing more support services and experiencing fewer barriers to care.

Chapter Four: Method

Overview

Data were collected as part of a larger study conducted at the University of Pennsylvania, which explored newly diagnosed children with ASD and factors related to their parents' decisions about whether to engage in treatment and how to obtain treatment and services. The children were evaluated at The Children's Hospital of Philadelphia and invited to participate in a research study by their diagnosing physician. The current study explored stress associated with raising a child newly diagnosed with autism throughout the first 6 months by examining specific variables from the archived data set. Specifically, level of child symptoms, use of services and supports, and barriers to care were assessed to determine the applicability of these variables on stress at baseline and over a 6-month time period.

Design and Design Justification

The original study used a longitudinal design with three time points: baseline, six months, and 12 months. This design allowed for analysis of predictive associations between an initial diagnosis and parenting stress levels. In addition, questionnaires assessing various obstacles to obtaining the appropriate services for children on the autism spectrum, as well as use of social supports, were evaluated to provide a rich data set upon which to further examine the correlates of parental stress in this population.

Participants

Thirty-eight caregivers of children diagnosed with ASD participated in the study. Two participants were fathers and were excluded from further analyses. The mean age for mothers was 37 years of age, with a range of 22-58 years at the start of the study. Of the

mothers, 75% were Caucasian, 19% were African American, and 6% were Latino or Hispanic. Most mothers (86%) were married, 8% were never married, 3% were divorced, and 3% indicated "other."

The majority of participating families (55%) included two children, with the remaining distribution as follows: one child (14%), three children (19%), and four or more children (12%). No siblings were diagnosed with ASD; however, three siblings had been diagnosed with other developmental delays. In addition, 7% of siblings were reported to have other diagnoses (i.e., Downs syndrome, mild cerebral palsy, ADHD/anxiety, and learning disabilities).

Of the children diagnosed with ASD, 83% were male. More than half (53%) were diagnosed with Autism Spectrum Disorder/Pervasive Developmental Disorder (n = 19), 36% with Autistic Disorder (n = 13), and 11% with Asperger's Disorder (n = 4). The average age at diagnosis was 3.4 years, with a range of 1.8 - 11 years of age (*SD* 1.7). The majority (86%) were younger than 5 years of age when they were diagnosed. Three children were diagnosed at age 5 years (8%), one at age 7 years (2%), and one at age 11 years (2%). Comorbid medical conditions were also indicated in approximately 28% of the sample, including mild cerebral palsy (1), Downs syndrome (1), phenylketonuria (1), and heart conditions (2). An additional 11% of the sample reported allergies, and the remaining 61% reported no comorbid medical conditions.

Inclusion Criteria

Parents enrolled in the study had to have a child with a new diagnosis on the autism spectrum (within the previous 4-12 weeks). If the child had a previous diagnosis, he or she was still enrolled in the study as long as the previous diagnosis was within 2

months of the second-opinion visit at The Children's Hospital of Philadelphia. ASD included the following diagnoses: ASD, PDD, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS), Asperger's Disorder, and Autism (Aut).

Exclusion Criteria

If the diagnosis was a second opinion and the family had been given a diagnosis longer than 2 months prior to the visit, they were excluded from this study. No restrictions were made based on child variables, including age, gender, or cognitive functioning; however, because of varying stress profiles of mothers and fathers, fathers were excluded for purposes of the current study (two fathers had participated in the original study).

Recruitment

Although this study used archival data, in the original study, a research assistant identified newly diagnosed children through a weekly review of billing slips at The Children's Hospital of Philadelphia. Identified families were mailed a letter of invitation to participate in a research study. The letter was signed by the child's attending physician and was accompanied by a flyer highlighting the purpose of the study and contact information for those interested in participating in the study. Flyers and contact information were also posted in the clinic for self-referrals.

Informed Consent Procedures

In the larger study, interested parents contacted the research assistant listed on the flyer to express interest in the study. After a phone screen was conducted to confirm eligibility, informed consent was obtained by phone, and then a hard copy of the consent

form was mailed to the participating parents, with one copy for them to keep and one to mail back for study records.

Measures

Demographic Questionnaire. This questionnaire was created for the larger study and included questions on ethnicity, caregiver age, family structure, parent education, and socioeconomic status.

Parenting Stress Index-Short Form (PSI-SF; Abidin, 1990). This measure contains 36 statements that are rated on a 5-point Likert type scale ranging from *strongly agree* to *strongly disagree*. It yields three subscales, (a) Parental Distress, (b) Parent-Child Dysfunctional Interaction, and (c) Difficult Child, and includes a validity scale. Scores at or above the 85th percentile are considered clinically significant. Good evidence of content validity (Burke, 1978; Kazak & Marvin, 1984), concurrent and construct validity (Abidin, 1983; Loyd & Abidin, 1985), and discriminant and factorial validity (Abidin, 1983) have been reported. Questions on the short-form are identical to items on the full-scale version and were selected through a factor analysis for a more efficient and less time-consuming means of collecting data on parent stress.

Child Behavior Checklist (CBCL; Achenbach & Rescorla, 2001). This measure is a 140-item, self-administered measure completed by caregivers about the child and is generally completed in 10-25 minutes. Questions are rated on a 3-point Likert-type scale (0 = *not true of child*; 1 = *sometimes or somewhat true*; 2 = *very or often true*). Subtests and scores are included for the following symptom subscales: Attention Problems, Emotionally Reactive, Withdrawn, Somatic, Anxious/Depressed, and Sleep Problems. *DSM*-oriented scales include Anxious/Depressed, Attention Deficit

Hyperactivity Disorder (ADHD); Affective Problems, Oppositional Defiant Disorders; and Pervasive Developmental Problems (American Psychiatric Association, 2013). The two versions depend on the age of the target child (1 ½-5 and 6-18 years of age), and some variability in terms of subscales exists between versions. Competence items included for older children look at children's activities, social relations, and school adaptability. Lastly, some language information is gathered through a word count and sample phrases typically used by the child on the 1 ½ -5-year-old form. Interrater reliability of 0.93-0.96 and internal consistency values of 0.78-0.97 have been cited (Achenbach 1991, 2009; Achenbach & Ruffle, 2000).

Use of Supports and Services Questionnaire. This questionnaire is comprised of a list of 21 places parents may turn to for help with their child. Caregivers rate each option as a place they have "received help," "would consider" receiving help, or "wouldn't consider" turning to for help. Specific examples include "neurologist," "early intervention team," and "clergy person." This list is adopted from Hornblow and Poduska and is augmented with potential supports from outside the medical establishment (i.e., family members, religious institutions) and with other supports. Therefore, it provides a nice sampling of both formal and informal supports. This questionnaire was created for the larger study, and thus no validity/reliability data are available.

Barriers-to-Care Questionnaire. The Barriers-to-Care questionnaire is comprised of a list of 18 reasons parents sometimes give for not receiving treatment for their child. Parents are asked to rate each item "no/yes/don't know" in regards to whether each of the items has been a barrier for them when seeking treatment for their child.

Items address multiple factors, including financial (i.e., “Does health insurance cover the type of treatment you want?”), other people (i.e., “Do other family members object to your child receiving treatment?), and perception (i.e., “Do you think the treatment is helping?”). This questionnaire is based on instrumentation developed for the Methods for the Epidemiology of Child and Adolescent Mental Disorders (MECA) study and by Pavuluri, Luk, & McGee, 1996). This measure was created for the purposes of the larger study, and thus no validity/reliability data are available.

Procedures

In the original study, families who received a new ASD diagnosis at a The Children’s Hospital of Philadelphia were mailed flyers describing the study and requesting their participation. Interested families contacted the research coordinator by phone, at which time they were screened to verify eligibility to participate in the study. If criteria were met, informed consent was obtained by phone, and hard copies of the consent form were mailed to qualified participants. Over the next 12 months, parents participated in the study at three time points. During baseline, 6-month, and 12-month time points, questionnaires were mailed, completed, and sent back to the research coordinator. Participants were allowed a 3-month window to complete the 6-month and 12-month questionnaires. The research coordinator also conducted check-in phone calls at 3- and 9-month time points. This call served to verify contact information, remind parents of the next questionnaires to be sent, and informally ask if anything had changed since the last time they talked. If questionnaires were not returned within 2 weeks, phone and e-mail reminders were sent to the parents, and finally, a second set of questionnaires was mailed to encourage sufficient data collection at each time point. Finally, participants

were provided with $20 compensation for their time at 6-month and 12-month time points, a total $40 incentive. They also had the option to waive payment.

Archival data. The current study extracted specific information from the archived data set of the original study to further investigate child symptom levels, use of support services, barriers to care, and parental stress. An application to the Institutional Review Board (IRB) of The Children's Hospital of Philadelphia was submitted requesting access to this specific combination of de-identified variables. A person selected by the principal investigator of this study compiled a confidential database for use in the smaller proposed study, eliminating all extraneous information. In addition to the specific variables previously listed, the author requested ages of the child and parents, time elapsed between initial diagnosis and enrollment in the original study, and specific diagnostic category for each child. IRB approval was granted, and the de-identified data were created and sent via an encrypted, password-protected flash drive. Both the sender and receiver of the file utilized a secure e-mail server to exchange passwords to further ensure protection of the data.

Linear regression was utilized for the majority of analyses. The dependent variable was parental stress at 6 months as measured by the total parental stress score on the PSI-SF. The primary independent variables were use of social supports and barriers to care. The Use of Support and Services questionnaire included four options: "received help," "would consider," "would not consider," and "don't know". These data were recoded as follows: 1 = "received help"; 0 = "would consider", 0 = "would not consider", 0 = "don't know." This categorization allowed for a frequency count of the number of supports the caregiver actually received rather than would consider. The Barriers-to-Care

questionnaire required reverse coding of the following items: 1, 2, 8, 13, 14, and 15. Then, a total score was calculated to reflect a frequency count of the number of barriers to care reported by each participant. Covariates of interest included child behavioral problems and parental stress levels at baseline. Child behavioral problems were examined using the externalizing and internalizing behavior subscales, as well as the total score on the CBCL. Exploratory analyses were also conducted on parental distress, parent-child interaction, and difficult-child subscales of the PSI-SF.

Data were analyzed using SPSS statistical software. The data were tested for outliers, as well as for assumptions of normality. The Barriers-to-Care questionnaire failed tests of normality for both baseline and 6-month time points. Therefore, data from the Barriers-to-Care questionnaires were transformed into three categories (i.e., low, moderate, and high) to ensure a normal distribution. Analyses were completed to characterize the sample by including the caregiver's age, ethnicity, and marital status; the total number of children in the family; and the age, gender, diagnostic classification on the autism spectrum, and comorbid diagnoses of the child with ASD.

The bivariate associations among baseline measures of child behavioral problems, support services, and barriers to care on parental stress at 6 months were then assessed. Parental stress at 6 months was regressed onto the 6-month measures of use of support services and barriers to care. Only covariates with an unadjusted association at $p < .2$ were entered in the adjusted analysis to address the small sample size and present the most parsimonious statistical model. Finally, the potential moderating effect of social supports and barriers to care on the association between parental stress at baseline and 6 months was examined by testing the interaction between social supports and baseline

stress, and barriers to care and baseline stress. All variables were centered. Product variables (baseline stress X social support; baseline stress X barriers to care) were then calculated to evaluate the potential interaction effects. The .05 level of significance was used for all statistical tests unless otherwise noted.

Chapter Five: Results

This longitudinal design consisted of a single group of mothers evaluated at two time points: initial diagnosis and 6-month follow-up. All parents received an initial ASD diagnosis for their child (i.e., within 4-12 weeks of this study), and thus no manipulation by the researcher took place. Approximately 17% of the variance in parental stress scores at 6 months was accounted for by baseline stress scores ($p = .020$).

Means, standard deviations, and correlations among parental stress, social support, and Barriers-to-Care variables are reported in Table 1. Bivariate analyses indicated that child behavioral problems, use of support services, and barriers to care at baseline were not associated with parental stress at 6 months ($p < .2$; see Table 2). Total stress score at baseline, barriers to care at 6 months, and use of support services at 6 months were entered into a linear regression simultaneously (see Table 2). Approximately 28% of the variance in total parental stress scores at 6 months was accounted for by these three variables ($p = .008$). Each variable was statistically significantly associated with total parental stress scores at 6 months in the adjusted model (see Table 3).

The interaction term between use of support services at 6 months and stress at baseline was not statistically significant ($p = .523$). The interaction between barriers to care at 6 months and stress at baseline was ($p = .112$).Although not statistically significant the interaction did demonstrate marginal significance worthy of note given the small sample size. Further investigation of the potential interaction effect between stress at baseline and barriers to care on total stress at six months was deemed appropriate given the small sample size of the study and the marginal significance of the interaction term.

Table 1

Means, Standard Deviations, and Correlations for Total Stress Score at 6 Months and Baseline Total Stress, 6 Month Social Supports, 6 Month Barriers-to-Care Predictor Variables

Variable	*M*	*SD*	StressB	Support6	Barriers6
Total stress @ 6 months	94.5	18.0	.416*	.242	.237
Predictor variable					
Total stress @ baseline	101.6	19.8	--	-.048	.080
Support Services @ 6 months	9.1	3.3	-.048	--	-.382*
Barriers to care @ 6 months	2.8	1.9	.080	-.382*	--

Note. StressB = Total stress at baseline; Support6 = Total use of support services at 6 months; Barriers6 = Total barriers-to-care at 6 months.
* $p < .05$.

Table 2

Bivariate Association Results for Predictor Variables on Total Parent Stress at 6 Months

Variable	β	*p*
PSI total stress score	0.42	.020*
CBCL total score	0.02	.956
Support services at Baseline	0.42	.668
Barriers to care at baseline	1.4	.419
Support services at 6 months	1.3	.189*
Barriers to care at 6 months	2.2	.199*

Note. PSI = Parenting Stress Index; CBCL = Child Behavior Checklist.
* $p < .2$

Table 3

Multiple Regression Analysis Summary for Support Services and Barriers to Care Predicting Parental Stress at 6 Months Controlling for Parental Stress at Baseline

Predictor variable	β	p
Total stress at baseline	0.4	.015*
Support services at 6 months	2.1	.029*
Barriers to care at 6 months	3.3	.043*

* $p < .05$.

Therefore, total stress at baseline was categorized into two groups representing low and high stress. The clinical cut-off score of 90 or above was utilized to separate the two groups based on recommendations by the authors (Abidin, 1990). The barriers-to-care variable was divided into three categories: low, moderate, and high levels of reported barriers. Stress at baseline (low and high groups), barriers to care (low, moderate, high), their interaction term, and use of support services at 6 months were entered into a multiple regression analysis. Approximately 33% of the variance in total parental stress scores at six months was accounted for by this model ($p = .006$). Each variable was statistically significantly associated with total parent stress scores at six months with the exception of the product term ($p = .118$).

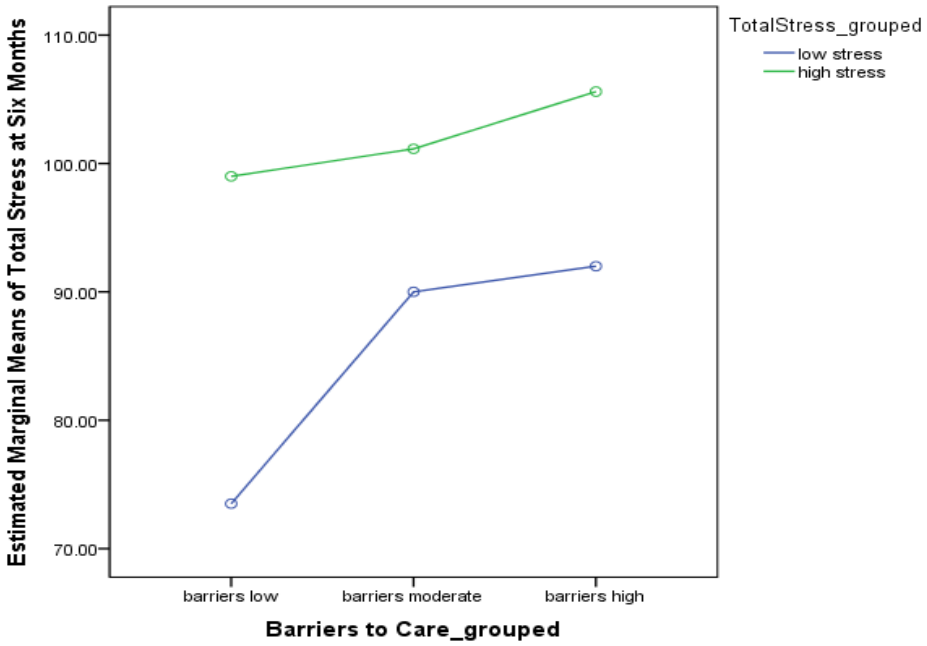

Figure 2. *Barriers to care on total stress score from baseline to 6 months post diagnosis.*

Chapter Six: Discussion

Parenting a child with ASD is a journey that begins with initial concerns of parents that something may not be “quite right” with their child. Caregivers receive a diagnosis for their child, begin a marathon of visits to professionals, navigate services and supports, and obtain the most appropriate treatment for their child. Once initial treatments are started, future worries continue to arise as the child’s developmental trajectory changes and unfolds over time. Therefore, decades of research not surprisingly demonstrate that the majority of parents of children with ASD report clinically significant levels of stress (Cassidy et al., 2008; Pottie & Ingram, 2008). Parental stress in this population is higher than in parents of typically developing children and those with other diagnoses (Crnic & Greenberg, 1990; Fisman et al., 2000; Hastings et al., 2006; Hoffman et al., 2009; Zeanah et al., 2011). Consistent with results of previous research, findings of the current study indicate 60% of the sample reported stress levels above the clinical cut-off at the time of initially receiving the diagnosis. More alarming is that 67% of those identified in this study with clinically significant stress levels at baseline maintained that level of stress as reported 6 months later. Given the consistent and chronic levels of stress in caregivers of those with ASD, the purpose of this investigation was to determine the relationship between support services and barriers to care on stress levels of mothers with a newly diagnosed child with ASD. Specifically, it was hypothesized that both decreased barriers to care and increased use of support services would moderate the relationship between parental stress at baseline and 6 months post diagnosis controlling for child behavioral problems at baseline.

Study results provided tentative support for the importance of barriers to care in the understanding of parental stress. The interaction between baseline stress and barriers to care illustrated a value approaching significance but was not definitive. The absence of clinical significance may be the result of factors including the limited sample size and/or specific time period examined in this study (i.e., 6 months). For instance, this period of time may have been too long to adequately capture stress levels and/or barriers to care. Therefore, although the association between baseline stress and barriers to care did not reach the threshold of statistical significance, it did approach a level of clinical value worthy of comment. Particularly, it suggests that increasing stress and barriers to care at the same time is likely related to an overall decrease in stress over time. Although contrary to the expected direction, parents experiencing long-term levels of chronic stress appear to become more efficient with the application of coping skills. Therefore, this group of resilient mothers may not be as sensitive to the introduction of additional stressors or may be better equipped to cope with ensuing stressors. Additionally, statistical analyses may not `accurately capture further rises in stress levels of parents who start with clinically significant levels at baseline, which may be explained by a ceiling effect. Lastly, the effect of barriers to care on parents experiencing high levels of stress at baseline may be reflected in other ways. Specifically, other mental-health issues are not represented in the stress measure, and this group of mothers may go on to experience more clinically significant mental-health concerns, such as depression or anxiety, which are often clinically reported in families raising children with autism. Furthermore, differentiation can be observed once the sample was divided into a low- and

high-stress group, illustrating the specific impact of barriers to care on parental stress levels in this sample.

In the case of mothers with low stress at baseline, a stark contrast emerged showing that increased barriers to care were associated with a noteworthy escalation in stress at 6 months. Specifically, among mothers with low stress at baseline, those who experienced even moderate barriers to care had an 18-point higher average stress at 6 months (M = 101.6) than mothers who experienced low barriers to care. Some evidence suggests that obtaining a diagnosis is perceived to be the "hardest part" of a parents' journey to help their child. For instance, one parent reported, "I'm going to get the autism diagnosis, and all these services are going to fall out of the sky, and we're going to be helped" (Minnes & Steiner, 2009, p. 253). Receiving a diagnosis can provide validation for the concerns of a parent; however, parents may assume that the finality of a diagnosis will automatically start the appropriate treatment interventions without further difficulty. Unfortunately, such is not the case for the majority of parents, as a critical need for autism advocacy continues in such areas as public policy, legislation, and licensure of qualified professionals to provide such services. Therefore, the subset of mothers illustrating low levels of stress at the time of diagnosis experience striking hikes in stress levels as a result of even moderate levels of barriers to care. This finding has important implications for parental stress intervention programs. Specifically, it suggests that stress management programs may be more successful in targeting the group of parents illustrating low levels of stress at the time of diagnosis in an effort to circumvent an increase in stress over time. Providing additional information to caregivers at the time of diagnosis may afford necessary guidance to minimize barriers to care. Implementing

parental support programs in a manner that empowers caregivers to feel confident in their ability to parent a special-needs child is also important. Additionally, gathering detailed information about this select group of mothers who are able to manage stress levels at least initially would assist in developing more effective long-term stress management programs for parents of children with ASD.

In regard to social supports, results of this study did not support the hypothesis that the use of more supports would result in less stress. In fact, the current study indicated a higher number of social supports to be associated with a minimal 2-point increase in stress scores at 6 months ($\beta = 1.9$); ($M = 101.6$). Previous research on social support and stress in this population has been mixed; therefore, this finding is not unexpected (Cassidy et al., 2008; Deater-Deckard, 1998; Smith et al., 2001; Thomas et al., 2007). However, the relationship between social supports and barriers to care on parental stress levels remains unclear. For instance, correlational analysis indicated a moderate negative relationship in which the higher the number of support services the fewer the number of reported barriers to care ($r = -.382$). This relationship can be explained as the information parents receive from support services may help to mitigate potential barriers to obtaining care. More social supports were found to be associated with a lower number of barriers to care, suggesting that more social supports would result in less stress; however, this study found an association between higher social supports and small increases in levels of stress. Support services might mitigate the number of barriers to care experienced by parents; however, residual stress may remain from the process of obtaining supports to circumvent barriers to care. Taken together, more

research is warranted to determine the precise contribution of each as well as the combined influence of social supports and barriers to care on parental stress levels.

Contrary to previous research illustrating a convincing argument regarding the relationship between child behavioral problems and parental stress, the current study did not support the hypothesized relationship (Freeman et al., 1991; Hastings et al., 2006; Lecavalier et al., 2006; Rao & Beidel, 2009; Weiss & Lunsky, 2011). No predictive value of child behavioral problems was found in determining parental stress levels at baseline. This null finding may be explained, in part, by the lapse in time between the two recorded measures. Specifically, parents submitted the child behavior questionnaire prior to receiving their initial appointment at the clinic, and these data were collected retrospectively by the original research team through a chart review. Data were not available to calculate the exact duration of time between the completion of the child behavior measure and the feedback appointment during which the initial diagnosis was provided by a developmental pediatrician; however, anecdotal reports indicate this time period varied greatly from a few weeks to multiple months depending on wait list time. As a result, a period of a few months might have separated the parent report of child behavior symptomatology and initial parent stress levels. Since the two measures had not been collected simultaneously, a different outcome may have resulted if measures had been reported at the exact same point in time. Furthermore, there was no predictive value of child behavioral problems at baseline to stress levels six months later. It is important to note that a measure of child behavior problems was not available at the second time point to control for changes in behavioral presentation over time (i.e., intensity, frequency, duration). The fact remains that parents of children with ASD have higher levels of stress

than parents of children with other disorders, even when the impact of child behavioral problems is controlled.

Limitations

The participants in this study constituted a small sample (N = 36) of the larger population of caregivers of children with ASD, making the application of these results difficult across the spectrum that encompasses an ASD diagnosis. Additionally, findings cannot be generalized to the population at large, as the vast majority of participating mothers were Caucasian, married, and had two or more children.

The baseline measures for this study were collected within 4-12 weeks of receiving the diagnosis, a discrete period during which other factors may have occurred to influence self-reported parental stress. For instance, in the first month after receiving a diagnosis for their child, parents may have informed extended family members, begun the process of obtaining specialty services for ASD, and had an opportunity to process the diagnosis and its meaning for their family. Therefore, ensuring a measure of parental stress closer to the time of diagnosis and following changes more regularly over time may be of value. Additionally, there was no measure of child behavior at the second time point; therefore, measuring changes in child symptomatology over time was not possible. Changes in child behavior over time might have had some impact on parental stress levels, the number of support services sought by parents, and the experienced barriers to obtaining care. Specifically, some evidence suggests that respite care is more difficult to obtain when the child is exhibiting behavioral problems (Sanders & Morgan, 1997; Young et al., 2009).

Future Research

There is a substantial amount of research establishing clinically significant levels of stress in the majority of parents caring for a child with ASD (Hastings et al., 2006; Hoffman et al., 2009; Zeanah et al., 2011). Many areas have been explored in understanding the mechanisms contributing to this phenomenon; however, a causal relationship remains unclear. Results of the current study suggest a multivariable approach to future research in furthering the understanding and specific contributors to parental stress levels. First, the current study provides preliminary support that the minority of families who do not report clinically significant levels of stress at the time of diagnosis may experience striking hikes in stress levels as a result of experiencing barriers to care. Therefore, families that are able to maintain "manageable" levels of stress at such a challenging time should be the target of further examination. These parents may provide useful information regarding the most effective ways to assist the more commonly observed group of parents that demonstrate clinically significant levels of parental stress. Specifically, expanding the work of Greeff & van der Walt (2010) to include coping styles and self-efficacy is warranted.

Second, further exploration of the specific elements of barriers to care will be important in understanding the contributions to parental stress in those otherwise "resilient" to clinically high levels. Expanding the measure of barriers to care to include additional details (i.e., specific frequencies, durations, and Likert scale ratings) may help to define the most salient aspects influencing parental stress in this population. Barriers to care associated with other disorders of childhood may be a useful avenue for future research to isolate differences in child symptomatology specific to ASD in comparison to

other disorders (i.e., ADHD, chronic medical conditions). In regards to barriers to care, further research should collect additional information regarding specific details of parental obstacles in obtaining treatment (i.e., quality of services, funding sources, health insurance coverage for treatment, state laws requiring coverage of autism treatments by health insurance, health insurance coverage mandates). Moreover, separating objective (e.g., "Would you experience transportation problems in seeking treatment?") and subjective (e.g., "Do you trust the professionals working with your child?") aspects of barriers to care may be helpful. Furthermore, a comparison between mothers and fathers is also needed, as research suggests that fathers experience stress in a different manner than mothers. Therefore, investigating if a similar pattern would emerge in the influence of barriers to care on paternal stress would be interesting.

The current study illustrated higher use of social supports to be associated with a slight increase in parental stress levels; however, breaking down social supports into more specific categories, such as the formal help of professionals versus informal resources, such as parent groups and family friends may be useful. Although the current study did not find any significant differences between "formal" and "informal" sources of supports, the measure utilized was not standardized to address these categorical differences, and groupings were formed on a subjective basis. Furthermore, the measures utilized for support services did not include an exhaustive list of potential sources of assistance. For instance, supports and services did not include Applied Behavior Analysis (ABA) therapists, an evidenced-based teaching intervention for children with ASD. Evidence also exists supporting the value of professional social support to improve parent's self-efficacy (Brookman-Frazee, 2004; Dunst & Trivette, 1987). Perhaps even

more important have been studies that have found low self-efficacy to be related to high parental stress levels (Petrongolo, 2005; Scheel & Rieckmann, 1998). Therefore, future research should combine these variables to explore a possible moderating relation among barriers to care, social support, and self-efficacy on stress levels of parents with a child on the autism spectrum.

A comprehensive system to measure child behavioral problems and specific symptomatology of ASD across time is important to allow differentiation of the root of parental stress levels. Although the current study did not support the association between child behavioral problems and parental stress, previous researchers have found significant support for this relation. The current study aimed to explore the experience of parents in the first 6 months after obtaining an initial diagnosis, regardless of child age. Although this study did not find any differences in parental stress between those with a younger child (3 years of age and younger) versus an older child (older than 3 years of age), a larger sample may indicate differences relative to age at the time of diagnosis and is therefore worthy of further investigation.

The current study did not indicate a change in parental stress levels over the initial 6 months post diagnosis; however, future research should extend the target time period to examine stress levels over longer periods of time to determine if stress levels remain consistent. More regular time points (i.e., every 3 months) may also assist in the understanding of the transformation of parental stress over time in hopes of developing a parental support system throughout the life span of a child with ASD to manage parental stress levels and support an optimal quality of life for each family. Overall, this study provides preliminary evidence to support the importance of barriers to care in the

understanding of parental stress with children with an ASD. Therefore, future studies should investigate the specific elements that compose reported barriers to care as well as generalize findings beyond the sample of mothers represented in this study (i.e., fathers, parenting multiple children with ASD). This line of research is all in the best effort to develop the most effective support programs for parents raising children with ASD, a growing epidemic in early-childhood mental health.

References

Abbeduto, L., Seltzer, M., Shattuck, P., Krauss, M., Orsmond, G., & Murphy, M. M. (2004). Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome. *American Journal on Mental Retardation, 109*, 237-254.

Abidin, RR. (1983). *Parenting stress index: Manual.* Pediatric Psychology Press, Charlottesville, VA.

Abidin R. R. (1990). *Parenting stress index: Manual* (3rd ed.). Pediatric Psychology Press, Charlottesville, VA.

Achenbach, T. M. (1991). *Integrative guide for the 1991 CBCL/4-18, YSR, and TRF profiles*. Burlington: University of Vermont, Department of Psychiatry.

Achenbach, T. M. (2009). *The Achenbach system of empirically based assessment (ASEBA): Development, findings, theory, and applications*. Burlington: University of Vermont Research Center for Children, Youth, and Families.

Achenbach, T. M., & Rescorla, L. A. (2001). *Manual for the ASEBA school-age forms & profiles*. Burlington: University of Vermont, Research Center for Children, Youth, and Families.

Achenbach, T. M., & Ruffle, T. M. (2000). The Child Behavior Checklist and related forms for assessing behavioral/emotional problems and competencies. *Pediatrics in Review, 21*, 265-271.

American Academy of Pediatrics, Medical Home Initiatives for Children with Special Needs Project Advisory Committee. The medical home. (2002). *Pediatrics, 110*, 184-186.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th edition.) Arlington, VA.

Antonovsky A. (1979). *Health, stress and coping.* San Francisco, CA: Jossey-Bass.

Baker, B. L., McIntyre, L. L., Blacher, J. J., Crnic, K. K., Edelbrock, C. C., & Low, C. C. (2003). Pre-school children with and without developmental delay: Behavior problems and parenting stress over time. *Journal of Intellectual Disability Research*, *47*(4-5), 217-230.

Baker-Ericzén, M. J., Brookman-Frazee, L., & Stahmer, A. (2005). Stress levels and adaptability in parents of toddlers with and without autism spectrum disorders. *Research and Practice for Persons with Severe Disabilities, 30*(4), 194-204.

Baxter, C., Cummins, R. A., & Polak, S. (1995). A longitudinal study of parental stress and support: From diagnosis of disability to leaving school. *International Journal of Disability, Development and Education*, *42*(2), 125-136.

Behr, S. K., Murphy, D. L., & Summers, J. A. (1992). *Kansas Inventory of Parental Perception (KIPP)*. The University of Kansas.

Bennett, T., Rowe, V., & DeLuca, D. (1996). Getting to know Abby. *Focus on Autism and other Developmental Disabilities*, *11*(3), 183-188.

Bishop, S. L., Richler, J., Cain, A. C., & Lord, C. (2007). Predictors of perceived negative impact in mothers of children with autism spectrum disorder. *American Journal on Mental Retardation*, *112*(6), 450-461.

Blacher, J. J., & McIntyre, L. L. (2006). Syndrome specificity and behavioral disorders in young adults with intellectual disability: Cultural differences in family impact. *Journal of Intellectual Disability Research, 50*(3), 184-198.

Bölte, S. & Poustka, F. (2002). The relation between general cognitive level and adaptive behavior domains in individuals with autism with and without co-morbid mental retardation. *Child Psychiatry and Human Development, 33*(2), 165-172.

Bolton, P. F., Golding, J., Emond, A., & Steer, C. D. (2012). Autism spectrum disorder and autistic traits in the Avon longitudinal study of parents and children: Precursors and early signs. *Journal of the American Academy of Child & Adolescent Psychiatry, 51*(3), 249-260.

Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and other Developmental Disabilities, 17*(4), 208-215.

Brachlow, A. E., Ness, K. K., McPeeters, M. L., & Gurney, J. G. (2007). Comparison of indicators for a primary care medical home between children with autism or asthma and other special health care needs. *Archives of Pediatric and Adolescent Medicine, 161,* 399-405.

Bristol, M. M. (1984). Family resources and successful adaptation to autistic children. In E. Schopler & G. B. Mesibov (Eds.), *The effects of autism on the family* (pp. 289-310). New York, NY: Plenum Press.

Brookman-Frazee, L. (2004). Using parent/clinician partnerships in parent education programs for children with autism. *Journal of Positive Behavior Interventions, 6*(4), 195-213.

Burke, W. T., & Abidin, R. R. (1978). *The development of Parental Stress Index.* Communication presented to APAC, Div. 37, Toronto: Canada.

Burke, P., & Cigno, K. (1996). *Support for families*. Aldershot: AveburyBurke & Cigno.

Cappe, E., Wolf, M., Bobet, R., & Adrien, J. L. (2011). Quality of life: A key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programs. *Quality of Life Research*, 20(8), 1279-94.

Carlson-Green, B., Morris, R. D., & Krawiecki, N. (1995). Family and illness predictors of outcome in pediatric brain tumors. *Journal of Pediatric Psychology, 20*(6), 769-784.

Carr, J. (2005). Families of 30-35-year olds with Down's syndrome. *Journal of Applied Research in Intellectual Disabilities, 18*(1), 75-84.

Carter, A. (2005). Stress reduction for parents of children with autism: A comparison of stress inoculation training and social support. *Dissertation Abstracts International, 65.*

Casey, L., Zanksas, S., Meindl, J. N., Parra, G. R., Cogdal, P., & Powell, K. (2012). Parental symptoms of posttraumatic stress following a child's diagnosis of autism spectrum disorder: A pilot study. *Research in Autism Spectrum Disorders*, *6*(3), 1186-1193.

Cassidy, A., McConkey, R., Truesdale-Kennedy, M., & Slevin, E. (2008). Preschoolers with autism spectrum disorders: The impact on families and the supports available to them. *Early Child Development and Care, 178*(2), 115-128

Centers for Disease Control and Prevention. (2014). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. Retrieved from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm?s_cid=ss6302a1_w

Chakrabarti, S., & Fombonne, E. (2001). Pervasive developmental disorders in preschool children. *JAMA: Journal of the American Medical Association, 285*(24), 3093-3099.

Crnic, K. A., & Greenberg, M. T. (1990). Minor parenting stresses with young children. *Child Development, 61*(5), 1628-1637.

Dabrowska, A. A., & Pisula, E. E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research, 54*(3), 266-280.

Daley, D., Sonuga-Barke, E. S., & Thompson, M. M. (2003). Assessing expressed emotion in mothers of preschool AD/HD children: Psychometric properties of a modified speech sample. *British Journal of Clinical Psychology, 42*(1), 53-67.

D'Angelo, S. L., & Omar, H. A. (2003). Parenting adolescents. *International Journal of Adolescent Medicine and Health, 15*(1), 11-19.

Davis, N., & Carter, A. S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders, 38*(7), 1278-1291.

Deater-Deckard, K. (1998). Parenting stress and child adjustment: Some old hypotheses and new questions. *Clinical Psychology: Science and Practice, 5*(3), 314–332.

Deater-Deckard, K., & Scarr, S. (1996). Parenting stress among dual-earner mothers and fathers: Are there gender differences? *Journal of Family Psychology, 10*, 45-59.

Donenberg, G., & Baker, B. L. (1993). The impact of young children with externalizing behaviors on their families. *Journal of Abnormal Child Psychology: An Official Publication of the International Society for Research in Child and Adolescent Psychopathology*, *21*(2), 179-198.

Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development. *Exceptionality*, *2*(2), 97-110.

Dunn, M. E., Burbine, T., Bowers, C. A., & Tantleff-Dunn, S. (2001). Moderators of stress in parents of children with autism. *Community Mental Health Journal, 37*, 39-52.

Dunninga, M. J., & Giallo, R. (2012). Fatigue, parenting stress, self-efficacy and satisfaction in mothers of infants and young children. *Journal of Reproductive and Infant Psychology*, *30*(2), 145-159.

Dunst, C. J., & Trivette, C. M. (1987). Enabling and empowering families: Conceptual and intervention issues. *School Psychology Review*, *16*(4), 443-456.

Dunst, C. J., Trivette, C. M., & Cross, A. H. (1986). Mediating influences of social support: Personal, family, and child outcomes. *American Journal of Mental Deficiency, 90*(4), 403-417.

Dyson, L. L. (1997). Fathers and mothers of school-age children with developmental disabilities: Parental stress, family functioning, and social support. *American Journal on Mental Retardation*, *102*(3), 267-279.

Edwards, J. (2003). Review of 'Being Alive'. *Psychodynamic Practice: Individuals, Groups and Organizations*, *9*(1), 94-99.

Efstratopoulou, M., Janssen, R., & Simons, J. (2012). Differentiating children with attention-deficit/hyperactivity disorder, conduct disorder, learning disabilities and autistic spectrum disorders by means of their motor behavior characteristics. *Research in Developmental Disabilities*, *33*(1), 196-204.

Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism*, *13*(4), 375-387.

Factor, D. C., Perry, A., & Freeman, N. (1990). Brief report: Stress, social support, and respite care use in families with autistic children. *Journal of Autism and Developmental Disorders*, *20*(1), 139-146.

Fisman, S., Wolf, L., Ellison, D., & Freeman, T. (2000). A longitudinal study of siblings of children with chronic disabilities. *The Canadian Journal of Psychiatry / La Revue Canadienne De Psychiatrie*, *45*(4), 369-375.

Flaherty, E. M., & Masters Glidden, L. (2000). Positive adjustment in parents rearing children with Down syndrome. *Early Education and Development*, *11*(4), 407-422.

Fombonne, E. (1999). The epidemiology of autism: A review. *Psychological Medicine: A Journal of Research in Psychiatry and the Allied Sciences*, *29*(4), 769-786.

Freedman, R. I., Griffiths, D., Krauss, M., & Seltzer, M. (1999). Patterns of respite use by aging mothers of adults with mental retardation. *Mental Retardation, 37*(2), 93-103.

Freeman, N. L., Perry, A., & Factor, D. C. (1991). Child behaviors as stressors: Replicating and extending the use of the CARS as a measure of stress: A research note. *Journal of Child Psychology and Psychiatry, 32*(6), 1025-1030.

Glidden, L., & Johnson, V. E. (1999). Twelve years later: Adjustment in families who adopted children with developmental disabilities. *Mental Retardation*, *37*, 16-24.

Gray, D. E. (1994). Coping with autism: stresses and strategies. *Sociology of Health & Illness, 16*(3), 275–300.

Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal Of Intellectual And Developmental Disability*, *27*(3), 215-222.

Gray, D. E. (2003). Gender and coping: the parents of children with high functioning autism. *Social Science & Medicine*, *56*(3), 631-642.

Gray, D. E., & Holden, W. J. (1992). Psycho-social well-being among the parents of children with autism. *Australia & New Zealand Journal of Developmental Disabilities, 18*(2), 83-93.

Greeff, A. P., & van der Walt, K. (2010). Resilience in families with an autistic child. *Education and Training in Autism and Developmental Disabilities, 45*(3), 347-355.

Guralnick, M. J., Hammond, M. A., Neville, B. B., & Connor, R. T. (2008). The relationship between sources and functions of social support and dimensions of child- and parent-related stress. *Journal of Intellectual Disability Research, 52*(12), 1138-1154.

Hall, H. R., & Graff, J. (2011). The relationships among adaptive behaviors of children with autism, family support, parenting stress, and coping. *Issues in Comprehensive Pediatric Nursing, 34*(1), 4-25.

Hall, A., Wood, D., Hou, T., & Zhang, J. (2007). Patterns in primary health care utilization among individuals with intellectual and developmental disabilities in Florida. *Intellectual and Developmental Disabilities, 45*(5), 310-322.

Hamlyn-Wright, S., Draghi-Lorenz, R., & Ellis, J. (2007). Locus of control fails to mediate between stress and anxiety and depression in parents of children with a developmental disorder. *Autism, 11*(6), 489-501.

Hastings, R. P. (2003). Child behavior problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research, 47*(4-5), 231-237.

Hastings, R. P. (2008). Stress in parents of children with autism. In E. McGregor, M. Núñez, K. Cebula, & J. Gómez (Eds.), *Autism: An integrated view from neurocognitive, clinical, and intervention research* (pp. 303-324).

Hastings, R. P., & Brown, T. (2002). Behavior problems of children with autism, parental self-efficacy, and mental health. *American Journal on Mental Retardation, 107*(3), 222-232.

Hastings, R. P., Daley, D., Burns, C., & Beck, A. (2006). Maternal distress and expressed emotion: Cross-sectional and longitudinal relationships with behavior problems of children with intellectual disabilities. *American Journal on Mental Retardation, 111*, 48-61.

Hastings, R. P., & Johnson, E. (2001). Stress in UK families conducting intensive home-based behavioral intervention for their young child with autism. *Journal of Autism and Developmental Disorders, 31*(3), 327-336.

Hastings, R. P., Kovshoff, H., Brown, T., Ward, N. J., Espinosa, F., & Remington, B. (2005). Coping strategies in mothers and fathers of preschool and school-age children with autism. *Autism, 9*(4), 377-391.

Herring, S. S., Gray, K. K., Taffe, J. J., Tonge, B. B., Sweeney, D. D., & Einfeld, S. S. (2006). Behavior and emotional problems in toddlers with pervasive developmental disorders and developmental delay: Associations with parental mental health and family functioning. *Journal of Intellectual Disability Research, 50*(12), 874-882.

Herring, M., & Wahler, R. G. (2003). Children's cooperation at school: The comparative influences of teacher responsiveness and the children's home-based behavior. *Journal of Behavioral Education, 12*(2), 119-130.

Hilliard, M. E., Monaghan, M. M., Cogen, F. R., & Streisand, R. R. (2011). Parent stress and child behavior among young children with type 1 diabetes. *Child: Care, Health and Development, 37*(2), 224-232.

Hoffman, C. D., Sweeney, D. P., Hodge, D., Lopez-Wagner, M. C., & Looney, L. (2009). Parenting stress and closeness: Mothers of typically developing children and mothers of children with autism. *Focus on Autism and other Developmental Disabilities*, *24*(3), 178-187.

Huws, J. C., Jones, R. P., & Ingledew, D. K. (2001). Parents of children with autism using an email group: A grounded theory study. *Journal of Health Psychology, 6*(5), 569-584.

Kanner, L. L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2*217-2250.

Kayfitz, A. D., Gragg, M. N., & Orr, R. (2010). Positive experiences of mothers and fathers of children with autism. *Journal of Applied Research in Intellectual Disabilities*, *23*(4), 337-343.

Kazak, A. E., & Marvin, R. S. (1984). Differences, difficulties and adaptation: Stress and social networks in families with a handicapped child. *Family Relations: An Interdisciplinary Journal of Applied Family Studies*, *33*(1), 67-77.

Keen, D., Couzens, D., Muspratt, S., & Rodger, S. (2010). The effects of a parent-focused intervention for children with a recent diagnosis of autism spectrum disorder on parenting stress and competence. *Research in Autism Spectrum Disorders*, *4*(2), 229-241.

Khanna, R., Madhavan, S., Smith, M. J., Patrick, J. H., Tworek, C., & Becker-Cottrill, B. (2011). Assessment of health-related quality of life among primary caregivers of children with autism spectrum disorders. *Journal of Autism and Developmental Disorders*, *41*(9), 1214-1227.

Knox, M., Parmenter, T. P., Atkinson, N., & Yazbeck, M. (2000). Family control: The views of families who have a child with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities, 13*(1), 17-28.

Koegel, R. L., Schreibman, L., Loos, L. M., & Dirlich-Wilhelm, H. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders, 22*(2), 205-216.

Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005–2006. *Pediatrics, 122*(6), 1149-1158.

Krauss, M. W., Upshur, C. C., Shonkoff, J. P., & Hauser-Cram, P. (1993). The impact of parent groups on mothers of infants with disabilities. *Journal of Early Intervention, 17*(1), 8-20.

Kwon, K., Han, S., Jeon, H., & Bingham, G. E. (2013). Mothers' and fathers' parenting challenges, strategies, and resources in toddlerhood. *Early Child Development and Care, 183*(3-4), 415-429.

Lau, A.S., Garland, A.F., Yeh, M., McCabe, K.M., Wood, P.A., & Hough, R. (2004). Race/ethnicity and informant discrepancies in assessing adolescent psychopathology. *Journal of Emotional and Behavioral Disorders. 12,* 145-156.

Lauritsen, M. B., Mors, O., Mortensen, P. B., & Ewald, H. (2002). Medical disorders among inpatients with autism in Denmark according to ICD-8: A nationwide register-based study. *Journal of Autism and Developmental Disorders, 32*(2), 115-119.

Lecavalier, L. L., Leone, S. S., & Wiltz, J. J. (2006). The impact of behavior problems on caregiver stress in young people with autism spectrum disorders. *Journal of Intellectual Disability Research, 50*(3), 172-183.

Lee, G. K. (2009). Parents of children with high functioning autism: How well do they cope and adjust? *Journal of Developmental and Physical Disabilities, 21*(2), 93-114.

Lessenberry, B. M., & Rehfeldt, R. (2004). Evaluating stress levels of parents of children with disabilities. *Exceptional Children, 70*(2), 231-244.

Levin, L., & Carr, E. G. (2001). Food selectivity and problem behavior in children with developmental disabilities: Analysis and intervention. *Behavior Modification, 25*(3), 443-470.

Levy, S. E., Mandell, D. S., Merhar, S., Ittenbach, R. F., & Pinto-Martin, J. A. (2003). Use of complementary and alternative medicine among children recently diagnosed with autistic spectrum disorder. *Journal of Developmental and Behavioral Pediatrics, 24*(6), 418-423.

Liptak, G. S., Stuart, T., & Auinger, P. (2006). Health care utilization and expenditures for children with autism: Data from U.S. national samples. *Journal of Autism and Developmental Disorders, 36*(7), 871-879.

Lovell, B., Moss, M., & Wetherell, M. A. (2012). With a little help from my friends: Psychological, endocrine and health corollaries of social support in parental caregivers of children with autism or ADHD. *Research in Developmental Disabilities*, *33*(2), 682-687.

Loyd, B. H., & Abidin. R. R. (1985). Revision of the Parent Stress Index. *Journal of Pediatric Psychiatry, 10*(2), 169-177.

Mackintosh, V. (2008). Expectations and stress related to choosing and providing treatment: A comparative study of parents of children with autism spectrum disorders or with Down syndrome. *Dissertation Abstracts International,* 68(10-B), 7002.

Maenner, M. J., Schieve, L. A., Rice, C. E., Cunniff, C., Giarelli, E., Kirby, R. S., Lee, L. C., Nicholas, J. S., Wingate, M. S., & Durkin, M. S. (2013). Frequency and pattern of documented diagnostic features and the age of autism identification. *The American Academy of Child & Adolescent Psychiatry* 52(4), 401-413

Mandell, D. S., Listerud, J., Levy, S. E., & Pinto-Martin, J. A. (2002). Race differences in the age at diagnosis among Medicaid-eligible children with autism. *Journal of the American Academy of Child & Adolescent Psychiatry*, *41*(12), 1447-1453.

Mandell, D. S., & Salzer, M. S. (2007). Who joins support groups among parents of children with autism?. *Autism*, *11*(2), 111-122.

Mandell, D. S., Wiggins, L. D., Carpenter, L. A., Daniels, J., DiGuiseppi, C., Durkin , M. S., Giarelli, E., Morrier, M. J., Nicholas, J. S., Pinto-Martin, J. A., Shattuck, P. T., Thomas, K. C., Yeargin-Allsopp, M., & Kirby, R. S., (2009). Racial/Ethnic disparities in the identification of children with autism spectrum disorders. *The American Academy of Child & Adolescent Psychiatry*, 99(3): 493–498.

Marc, D., & MacDonald, L. (1988). Respite care: Who uses it?. *Mental Retardation*, *26*(2), 93-96.

Martinez, V. (2010). The ecology of experiences and supports of mothers with children with autism spectrum disorder during the children's early years. *Dissertation Abstracts International: Section A, 71*.

Minnes, P. P., & Steiner, K. K. (2009). Parent views on enhancing the quality of health care for their children with fragile X syndrome, autism or Down syndrome. *Child: Care, Health and Development*, *35*(2), 250-256.

Oelofsen, N., & Richardson, P. (2006). Sense of coherence and parenting stress in mothers and fathers of preschool children with developmental disability. *Journal of Intellectual and Developmental Disability*, *31*(1), 1-12.

Olsson, M. B., & Hwang, C. P. (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research*, *45*(6), 535-543.

Osborne, L. A., McHugh, L., Saunders, J., & Reed, P. (2008). Parenting stress reduces the effectiveness of early teaching interventions for autistic spectrum disorders. *Journal of Autism and Developmental Disorders*, *38*(6), 1092-1103.

Östberg, M., & Hagekull, B. (2000). A structural modeling approach to the understanding of parenting stress. *Journal of Clinical Child Psychology*, *29*(4), 615-625.

Ozonoff, S. (2010). Autism spectrum disorders. In K. Yeates, M. Ris, H. Taylor, B. F. Pennington (Eds.), *Pediatric neuropsychology: Research, theory, and practice* (2nd ed.) (pp. 418-446). New York, NY: Guilford Press.

Pavuluri, M. N., Luk, S., & McGee, R. (1996). Help-seeking for behavior problems by parents of preschool children: A community study. *Journal of The American Academy of Child & Adolescent Psychiatry*, *35*(2), 215-222.

Perry, A. (1989). *Families of developmentally disabled children: Theoretical conceptualizations of stress and a proposed new integrative model.* Ph.D. Major Area Paper, York University, Toronto, ON.

Perry, A. (1990). *An empirical test of a new theoretical model of stress in families of children with autism.* Doctoral dissertation, York University, Toronto, ON.

Perry, A. (2004). A model of stress in families of children with developmental disabilities. *Journal on Developmental Disabilities*, 11, 1-16.

Petrongolo, M. (2005). *Aspects of social support, caregiver burden, and parental self efficacy in models of autism treatment: Subsequent impacts on parental stress levels.* (Unpublished master's thesis). Loyola College, Baltimore, MD.

Pisula, E. (2003). Parents of children with autism--review of current research. *Archives of Psychiatry and Psychotherapy*, *5*(4), 51-63.

Plienis, A. J., Robbins, F. R., & Dunlap, G. (1988). Parent adjustment and family stress as factors in behavioral parent training for young autistic children. *Journal of the Multihandicapped Person*, *1*(1), 31-52.

Pottie, C. G., Cohen, J., & Ingram, K. M. (2009). Parenting a child with autism: Contextual factors associated with enhanced daily parental mood. *Journal of Pediatric Psychology*, *34*(4), 419-429.

Pottie, C. G., & Ingram, K. M. (2008). Daily stress, coping, and well-being in parents of children with autism: A multilevel modeling approach. *Journal of Family Psychology*, *22*(6), 855-864.

Quittner, A. L., Barker, D. H., Cruz, I., Snell, C., Grimley, M. E., & Botteri, M. (2010). Parenting stress among parents of deaf and hearing children: Associations with language delays and behavior problems. *Parenting: Science and Practice*, *10*(2), 136-155.

Rao, P. A., & Beidel, D. C. (2009). The impact of children with high-functioning autism on parental stress, sibling adjustment, and family functioning. *Behavior Modification*, *33*(4), 437-451.

Rimmerman, A., Turkel, L., & Crossman, R. (2003). Perception of child development, child-related stress and dyadic adjustment: Pair analysis of married couples of young children with developmental disabilities. *Journal of Intellectual and Developmental Disability*, *28*(2), 188-195.

Rivers, J., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders*, *33*(4), 383-394.

Robbins, F. R., Dunlap, G., & Plienis, A. J. (1991). Family characteristics, family training, and the progress of young children with autism. *Journal of Early Intervention*, *15*(2), 173-184.

Rodrigue, J. R., Morgan, S. B., & Geffken, G. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology, 19*(4), 371-379.

Salovey, P., Rothman, A. J., Detweiler, J. B., & Steward, W. T. (2000). Emotional states and physical health. *American Psychologist, 55*(1), 110-121.

Sanders, J. L., & Morgan, S. B. (1997). Family stress and adjustment as perceived by parents of children with autism or Down syndrome: Implications for intervention. *Child & Family Behavior Therapy, 19*(4), 15-32.

Scheel, M. J., & Rieckmann, T. (1998). An empirically derived description of self-efficacy and empowerment for parents of children identified as psychologically disordered. *American Journal of Family Therapy, 26*(1), 15-27.

Sharpley, C. F., Bitsika, V., & Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability, 22*(1), 19-28.

Siman-Tov, A., & Kaniel, S. (2011). Stress and personal resource as predictors of the adjustment of parents to autistic children: A multivariate model. *Journal of Autism and Developmental Disorders, 41*(7), 879-890.

Singer, G. S. (2006). Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. *American Journal on Mental Retardation, 111*(3), 155-169.

Sivberg, B. (2002). Family system and coping behaviors: A comparison between parents of children with autistic spectrum disorders and parents with non-autistic children. *Autism*, *6*(4), 397-409.

Smith, K., Gabard, D., Dale, D., & Drucker, A. (1994). Parental opinions about attending parent support groups. *Children's Health Care*, *23*(2), 127-136.

Smith, T. B., Oliver, M. I., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry*, *71*(2), 257-261.

Snell, S. A., & Rosen, K. H. (1997). Parents of special needs children mastering the job of parenting. *Contemporary Family Therapy: An International Journal*, *19*(3), 425-442.

Solem, M., Christophersen, K., & Martinussen, M. (2011). Predicting parenting stress: Children's behavioral problems and parents' coping. *Infant and Child Development*, *20*(2), 162-180.

Spielberger, C. D., Gorsuch, R.L., and Lushene. R.E. (1970). *Manual for the State-Trait Anxiety Inventory.* Palo Alto, CA: Consulting Psychologists Press.

Steketee, G., Van Noppen, B., Lam, J., & Shapiro, L. (1998). Expressed emotion in families and the treatment of OCD. *In session: Psychotherapy in practice*, 4(3), 73-91.

Strickland, B., McPherson, M., Weissman,G., van Dyck, P., Huang, Z. J., & Newacheck,P. (2004). Access to the Medical Home: Results of the National Survey of Children with Special Health Care Needs. *Pediatrics*, 113(5), 1485-1492.

Tehee, E., Honan, R., & Hevey, D. (2009). Factors contributing to stress in parents of individuals with autistic spectrum disorders. *Journal of Applied Research in Intellectual Disabilities*, *22*(1), 34-42.

Thomas, K. C., Ellis, A. R., McLaurin, C., Daniels, J., & Morrissey, J. P. (2007). Access to care for autism-related services. *Journal of Autism and Developmental Disorders*, *37*(10), 1902-1912.

Tomanik, S., Harris, G. E., & Hawkins, J. (2004). The relationship between behaviors exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability*, *29*(1), 16-26.

Trute, B., Worthington, C., & Hiebert-Murphy, D. (2008). Grandmother support for parents of children with disabilities: Gender differences in parenting stress. *Families, Systems, & Health*, *26*(2), 135-146.

Tugade, M. M., & Fredrickson, B. L. (2004). Resilient individuals use positive emotions to bounce back from negative emotional experiences. *Journal of Personality and Social Psychology*, *86*(2), 320-333.

Valicenti-McDermott, M., Hottinger, K., Seijo, R., & Shulman, L. (2012). Age at diagnosis of autism spectrum disorders. *The Journal of Pediatrics*, *161*(3), 554-556.

Vostanis, P., Nicholls, J., & Harrington, R. (1994). Maternal expressed emotion in conduct and emotional disorders of childhood. *Journal of Child Psychology and Psychiatry*, *35*(2), 365-376.

Wagner, E. L. (2011). The parent check-up (pcu): Needs analysis, program development, service engagement, and feasibility in the applied behavior analysis setting. *Dissertation Abstracts International, 71*(9-B), 5808.

Wang, P., Michaels, C. A., & Day, M. S. (2011). Stresses and coping strategies of Chinese families with children with autism and other developmental disabilities. *Journal of Autism and Developmental Disorders, 41*(6), 783-795.

Weiss, J. A., & Lunsky, Y. (2011). The Brief Family Distress Scale: A measure of crisis in caregivers of individuals with autism spectrum disorders. *Journal of Child and Family Studies, 20*(4), 521-528.

Weiss, M. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism, 6*(1), 115-130.

Wilczynski, S. M., Fisher, L., Sutro, L., Bass, J., Mudgal, D., Zeiger, V., & ... Logue, J. (2011). Evidence-based practice and autism spectrum disorders. In M. A. Bray, T. J. Kehle (Eds.), *The Oxford handbook of school psychology* (pp. 567-592). New York, NY: Oxford University Press.

Wolf, L. C., Noh, S., Fisman, S. N., & Speechley, M. (1989). Brief report: Psychological effects of parenting stress on parents of autistic children. *Journal of Autism and Developmental Disorders, 19*, 157-166.

Yerkes, R. M., & Dodson, J.D. (1908). The relation of strength of stimulus of strength of rapidity of habit-formation. *Journal of Comparative Neurology and Psychology, 18*, 459-482.

Young, A., Ruble, L., & McGrew, J. (2009). Public vs. private insurance: Cost, use, accessibility, and outcomes of services for children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *3*(4), 1023-1033.

Zeanah, C. H., Berlin, L. J., & Boris, N. W. (2011). Practitioner review: Clinical applications of attachment theory and research for infants and young children. *Journal of Child Psychology and Psychiatry*, *52*(8), 819-833.